PATIENTS' AND PRACTITIONERS' VIEWS AND EXPERIENCES OF CHRONIC WIDESPREAD PAIN (FIBROMYALGIA) AND ITS MANAGEMENT IN THE UK AND LIBYA

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SEDIK A M ABOKDEER

This thesis is submitted in partial fulfilment of the requirements of the University of Northumbria at Newcastle for the degree of Doctor of Philosophy

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ABSTRACT

Patients' And Practitioners' Views And Experiences Of Chronic Widespread Pain (Fibromyalgia) And Its Management In The UK And Libya

Background & Aims: Chronic widespread pain conditions such as fibromyalgia are prevalent and costly to the economy. Diagnosis is based upon symptoms, and although fibromyalgia's existence as a distinct clinical entity is debated, it causes great suffering and distress for those affected. Due to the unclear pathophysiology, controversy regarding its existence as a clinical entity, and variability in diagnosis, clinical management is often difficult, and frequently employs heterogeneous interventions. In addition, there is a paucity of literature from Middle Eastern countries on the condition, where the diagnostic label is not used. The purpose of this research study is to capture service users' and service providers' views and experiences of fibromyalgia and its management, including their views on the journey to diagnosis, current practice availability, emotional and life experience, information seeking, and experiences of seeking and receiving health care. It also aims to compare current practice for fibromyalgia in the UK with Libyan management procedures for chronic widespread pain.

Research Method: A mixed methods approach was used in a two-phase study. Phase 1 consisted of twelve semi-structured interviews conducted with people diagnosed with FMS. The participants also completed the Fibromyalgia Impact Questionnaire (FIQ) and the Toronto Alexithymia Scale (TAS). Phase 2 consisted of a national survey of health and medical professionals from the British Pain Society and medical professionals in Libya regarding their views of and management practices for fibromyalgia. Findings were synthesised with qualitative findings

Results: Using framework analysis, the following themes were identified from the qualitative study: journey to diagnosis, coping with the varying and unpredictable nature of symptoms, emotional impact, and the availability and satisfaction with healthcare practices and services. The primary qualitative study highlighted some difficulties that the participants faced regarding a perceived lack of understanding by health and medical professionals as well as the general public regarding the management of the condition and its emotional and physical impact on their lives. These findings suggested that the

patients were not managing daily living activities due to the disabling fatigue and worsening pain. This was corroborated by high FIQ scores and high alexithymia scores. This part of the study has also illustrated that a variety of intervention approaches are used with varying and often limited success.

A total of n=69 respondents completed the survey, n=53 UK respondents and n=15 Libyan respondents The results indicated that increasing numbers of people are diagnosed with fibromyalgia, though a range of different diagnostic labels are used. Treatment approaches in both countries were primarily focused on exercise and education, with CBT being used in the UK. Respondents from both countries agreed that there was a strong psychological overlay, though there was a variation between opinions regarding whether active management should aggravate pain temporarily in order to increase functional gains.

Conclusions: The results indicate the high physical and emotional impact of fibromyalgia. The participants' perspectives have emphasised the need for support for people living with FMS, and the need for education and standardisation of approaches in clinical practice in both the UK and Libya.

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DECLARATION

I declare that the work contained in this thesis has not been submitted for any other award, and that all of the work is my own. I also confirm that all work ideas, contributions and opinions are fully acknowledged within this thesis.

Any ethical clearance for the research presented in this thesis has been approved. Ethical approval was sought and granted by the Department of Sport, Exercise and Rehabilitation Ethics Committee, Faculty of Health and Life Sciences, in May 2015 and February 2016 (HLSSA300415).

Name: Sedik Abokdeer

Signature:

Date: 10 / 06 /2019

PREFACE

Personal background, influences and beliefs

My interest in the area of chronic pain musculoskeletal disorders and such conditions as chronic low back pain CLBP and fibromyalgia began as I was nearing the end of my BSc in physiotherapy in the Faculty of Medical Technology at Nasser University. Libya 1997. For my dissertation, I had chosen the title of an acupuncture approach for the management of chronic low back pain. I then continued my studies to MSc in the UK, at Northumbria University Faculty of Health and Life Sciences where I undertook a systematic review for my dissertation into the management of chronic low back pain. Following my graduation in 2005 from Northumbria University, I then proceeded to work in Libyan Health Authority public sector for 10 years in the area of musculoskeletal interventions. In 2007, I began work as physiotherapy lecturer in Libya and endeavoured to teach physiotherapy elements, practice and neuro- management and I have been mindful of responsiveness of model of health within physiotherapy and wider health care provision. Continuing to Ph.D. level, I became interested in chronic widespread pain CWP such as Fibromyalgia FMS as from my clinical work, I observed interactions between these conditions and CLBP and Neck pain. I became interested in research in this broader area of CWP assessing, screening and interventions approaches. In addition to my clinical and research interests, in my personal life, around 2007, my mother was living with chronic pain with unrefreshed sleeping and depression treated by anti-depression (Amitriptyline), unclear instruction been established to diagnose her illness. Fibromyalgia and CWP is not generally diagnosed in Libya and this furthered my interest in this condition as it is recognised and diagnosed in Western countries. I realised that when I had read about this illness and who is affected her daily live activates and communications, I wanted to develop this area of research further. In regard to my background as physiotherapist, my aim was to know more about this condition and how it affected people who suffer these symptoms. From reading the research data, I found that there is also some variability in the UK and Western countries regarding diagnosis, experiences of healthcare. Initially I wanted to carry out a clinical trial, however this proved too difficult for several reasons and it was difficult to establish

a suitable control and standard care is not clearly defined and I then decided to first of all establish what this was in the UK and then to explore stakeholders views. Thus my clinical, academic and personal background has influenced this research from its inception to the data collection.

GLOSSARY OF TERMS

ACR 1990 criteria	American college of rheumatology criteria
ACTH corticotrophin	Adrenocorticotropic hormone corticotrophin
ADLs	Activities of Daily livings
ANS	Autonomic nervous system
ASD	Affective spectrum disorders
APS	American pain society
AV	Affairs veterans
BA	Body awareness
BPS	British pain society
BDI	Beck depression inventory
CAM	Complementary Alternative Medicine
CBC	Complete blood count
CBT	Cognitive behaviour therapy
CFS	Chronic fatigue syndrome
CLBP	Chronic low back pain
CNS	Central nervous system
CP	Chronic pain
CPAQ	Chronic Pain Acceptance Questionnaire
CPS	Canadian pain society
CRFs	Case report forms
CRH	Corticotropin-releasing hormone
CSF	Cerebrospinal fluid
DLA	Daily living activities
CWP	Chronic widespread pain
DIF	Difficult identifying feeling
DDF	Difficult describe feeling
DDD	Degenerative disc disease
EOT	Externally-oriented thinking
ESCAPE	Evaluation of Stepped Care for Chronic Pain
ESR	The erythrocyte sedimentation rate

EULAR	The European league against rheumatism
FIQ	Fibromyalgia impact questionnaire
FMS	Fibromyalgia syndrome
FSDC	Fibromyalgia survey diagnostic criteria
FSQ	Fibromyalgia survey questionnaire
HADS	Hospital anxiety and depression scale
HCPs	Health care professional prospective
HPA	Hypothalamic pituitary adrenal
IBS	Irritable bowel syndrome
IPA	interpretive phenomenology analysis
AIMS	Impact measurement scale
JM	Jenni Monaghan
LA	Latin American
MBSR	Mindfulness-based stress reduction
MCMQ	Medical Coping Modes Questionnaire
MMPI	Minnesota Multiphasic Personality Inventory
MRI	magnetic resonance image
MT	Massage therapy
MPQ	McGill pain questionnaire
MRC	Medical research council
MFIS	Modified fatigue impact scale
NHS	Health national services
OTs	Occupational therapy
PCPs	Primary care practitioners
PCS	Pain Catastrophising Scale
PNE	Pain neurophysiology education
PMS	Pain management specialist
Prelim ACR 2010 criteria	Preliminary ACR 2010 diagnostic criteria
PPI	Present Pain Intensity
PSEQ	Pain self-efficacy questionnaire
PTs	Physiotherapists
QoL	Quality of life
RA	Rheumatoid arthritis

RCT	Randomised control trials
SA	South Africa
SAS	Statistical analysis software
SS score	Somatic severity score
SSRIs	selective serotonin reuptake inhibitors
TAS	Toronto alexithymia scale
TENS	Transcutaneous electrical nerve stimulation
TMJ	Temporomandibular joint
TMD	Temporomandibular disorder
TPC	Tender point count
VAS	Visual analogue scale
WPI	Widespread pain index

CHAPTER ONE

INTRODUCTION AND REVIEW OF BACKGROUND LITERATURE

1.1 Introduction

Chronic widespread musculoskeletal pain conditions (CWP), such as fibromyalgia (FMS) are prevalent and costly to the economy (Hauser et al., 2009), with a higher proportion of females affected (Sim and Adams., 2002). Although well recognised, fibromyalgia is also a rather controversial syndrome, for which there are broadly accepted. Diagnostic criteria recognised and defined by the American College of Rheumatology 1990 where the operational diagnostic criteria are a chronic widespread pain (CWP) defined as pain in all four quadrants of the body, and pain in the axial skeleton for at least 3 months (Wolfe et al., 2010). Fibromyalgia is a multifactorial syndrome and is characterised by widespread pain and muscle tenderness, accompanied by debilitating fatigue and other comorbid symptoms, including psychological factors (Wolfe et al., 2010). Thus, diagnosis is based upon symptoms, and although fibromyalgia's existence as a distinct clinical entity is debated, it is accepted that the syndrome causes great suffering and distress for those affected, impacting both the affected individuals and their families. Fibromyalgia is costly to society, and places heavy demands and significant burden on the medical system. It has no specific diagnostic test and there is no 'cure' per se. It is widely reported within the western world, though prevalence varies, due to differing diagnostic practices. The condition is also reported in Middle Eastern countries, however the specific diagnosis of 'fibromyalgia' is not widely used. There is a paucity of literature regarding the diagnosis and management of the condition in the Middle East, and this will also be investigated in the current study, due to the professional background and experience of the researcher.

Affected individuals experience poor physical and social functioning and considerable distress. However, despite this, the condition is not well understood in terms of its pathophysiology. The aetiology is uncertain, but it is likely that the pathophysiology of FMS has both physical and psychosocial components.

Some studies have suggested an aetiological and perpetuating role of stress mechanisms involving the HPA axis (Abeles et al., 2007). Furthermore, it has been pointed out that the pathophysiology of FMS is complex and evolving, encompassing diverse issues such as disturbed patterns of sleep, altered cognitive impairment processing, decreased conditioned pain modulation at the spinal level, and increased

connectivity between various pain-processing areas of the brain. Depression and anxiety and the role of emotional processing have also been found to be important factors with the role of alexithymia and psychological distress implicated in the pain experience in FMS (Di Tella et al., 2017)The role of emotional factors will also be explored in this thesis.

Most clinicians realise that fibromyalgia is difficult to treat. Thus, consequent clinical management is often difficult, with heterogeneous interventions being employed, which can have variable outcomes. In the UK, it is difficult to ascertain what the standard care for FMS is and thus there are few UK based RCTs. As such, one aim of this research was define current practice within the UK, which is reported in chapter 5, upon which a future RCT could be designed and developed. Extant management approaches in Libya will also be explored and comparisons will be drawn.

Patients with FMS often report considerable dissatisfaction with existing services, which are often patchy and unavailable to this group (Hardy-Pickering), who found that many patients became frustrated with the lack of success of conventional treatments and accessed complementary or alternative medicine (CAM). One survey suggested that 91% of fibromyalgia sufferers had used some form of CAM (Ernst, 2009). This research explores the interventions that patients have accessed in both the NHS and privately and their views regarding conventional approaches, and why they may seek alternative forms of therapy and interventions or different management approaches. It also explores their sources of information about treatment options, as well as other factors that influence their decision-making.

In line with the current government initiatives, it is necessary to consult and consider the views of patients in developing evidence on which best practices are based. Thus, the central theoretical underpinning of this research study is evidence-based practice. The study examines current clinical practice, which has not yet been determined. Moreover, it also considers patients' experiences and their views of their conditions and the interventions they have received. These considerations are presented in Chapter 3.

1.2. Research Methodology

Complex interventions are usually described as interventions that contain several interacting components.(Craig, 2008), and are presented in the MRC Framework for Complex Interventions. There are, however, several dimensions of complexity, which may concern a range of possible outcomes or their variability in the target population, rather than the number of elements in the intervention package itself. Implementation research seeks to identify which techniques are effective in encouraging the conversion of evidence into practice, and provide information about 'real world' variability in the effectiveness and cost efficiency of interventions, and about the practicalities of introducing and sustaining new treatments or services (Pinnock 2003). Before it is possible to design an interventional study, it is first necessary to establish the existing evidence, define what is considered to be standard care in the UK, and explore the views of stakeholders. These points and considerations constitute the focus of this research study.

A mixed methods approach was adopted in this research using a qualitative and quantitative approach. This research seeks to describe important aspects associated with the FMS condition. Within this research, an exploration of existing literature in the field of health care professions, including a review of qualitative studies of patients' experiences of living with CWP, was conducted. Semi-structured interviews were conducted to capture the experiences of individuals with chronic pain. The study was inspired by the philosophical perspectives of epistemology, pragmatism, theoretical appraisal and critical reflection, where qualitative research can provide a contextual, in depth understanding of people's perspectives. The second phase of the study employed a descriptive survey to ascertain how FMS is managed within the UK by the various professions involved in the management of chronic widespread pain and the degree of variability of services within the UK and Libya. The purpose was to analyse the differences in approaches and explore attitudes and opinions regarding the outcome of fibromyalgia interventions that have been used in the clinical practice of rheumatologists, pain management specialists and physiotherapists. A survey was employed, and both quantitative and qualitative data was collected. The survey was developed based on an earlier study by Sim and Adams (2003b), who explored the management of fibromyalgia by physiotherapists and occupational

therapists. This study further investigates the management of fibromyalgia by a range of health professionals. This will enable the development of an interventional design with appropriate control groups for a future study, in which standard care can be defined.

1.3. Operational Definitions

For the purposes of this research, the fibromyalgia syndrome is considered to be a debilitating chronic disorder, characterized by the presence of continual and widespread musculoskeletal pain lasting three months or longer. Symptoms can include fatigue, sleep disturbance, tender points, anxiety and depression, cognitive deficits in attention, concentration and memory, and other symptoms such as irritable bowel syndrome, morning stiffness, headaches, or cramps (ACR 2010).

1.4 Review of Background Literature

To contextualise and provide evidence for this research study, a review of the relevant literature was conducted. The literature review was conducted in 2014, and subsequently updated in 2017. The following search terms and their combinations were used to search the CINAHL, COCHRANE, MEDLINE and PUBMED databases: 'fibromyalgia', 'pathophysiology', 'randomised controlled trial', 'experiences', 'physical functions', 'psychological variables', 'anxiety', 'depression', 'quality of life', 'coping', 'social support', 'musculoskeletal disorders', 'patient's education', 'pain management', ' cognitive behaviour therapy', 'non-pharmacological interventions', 'aerobics exercise', 'strengthening exercise', 'aquatics therapy', 'randomized control trial', and 'review article'. Grey literature was also searched to include key government reports on the subject. The reference lists in key studies provided a further source of literature.

1.4.1 Fibromyalgia Syndrome: An overview

Fibromyalgia, also known as fibromyalgia syndrome or FMS, is a disorder characterised by chronic widespread pain and fatigue. It is experienced in industrialized nations by up to 5% of the population (Clauw, 2007). In a review paper of the history of FMS and its diagnosis, the authors remarked that the condition causes widespread pain and muscle tenderness (sensitivity to touch) all over the body, leading

to non-refreshing sleep and generalized stiffness (Williams and Clauw., 2009).

These symptoms tend to be combined with a range of associated symptoms, such as irritable bowel syndrome, cognitive dysfunction, cold sensitivity, and depression, which can impact the lives of patients to varying degrees, as shown in Table 2.2.1. FMS is characterized by a variety of comorbidities, which makes it difficult to uniquely fit it into one illness classification. It is frequently co-morbid with other conditions, and a previous review of the history of the fibromyalgia syndrome found that it is often associated with abnormal stress reactivity and other psychological factors, with patients reporting that their symptoms worsened after physiological or mental stress and anxiety due to distressing occasions (Staud, 2007), thus resulting in compounding the condition.

Table 1.1: The main and the associated symptoms of the FMS disease

Main symptoms of FMS	Associated symptoms of FMS
Widespread muscular pain	Irritable bowel syndrome
Generalised stiffness	Cognitive dysfunction
Persistent fatigue	Exercise intolerance
Non-refreshing sleep	Anxiety and reactive depression
	Numbness and tingling
	Cold sensitivity
	Headaches
	Temporomandibular joint (TMJ) dysfunction
	Myofascial pain syndrome
	Raynaud's phenomenon
	Irritable bladder
	Dysmenorrhoea
	Skin disorders
	Multiple sensitivities
	Autonomic dysfunction

A survey study used a mailed questionnaire to a random sample of 533 adults with fibromyalgia over 50 years of age to measure the frequency and severity of distress caused by FMS symptoms(Shillam et al., 2011). The participants reported moderate functional limitations, however, it is worth noting that the impact of FMS extends beyond individual costs in the form of reduced quality of life, to causing a significant strain on society too. Depending on the seriousness of side effects, people with fibromyalgia have been found to miss somewhere between 5 to 39 days of work annually (Shillam et al., 2011). A USA study used administrative claims and data collected from n=4699 patients with FMS to compare FMS with other chronic conditions. Patients with FMS were found to be more incapacitated reportedly feeling

'wiped out', and had more than twice the yearly well-being expenses. The study findings suggested that, within the management of FMS, there may be large cost-offset opportunities for reductions in patient, physician, and employer burdens (Robinson et al., 2003).

The diagnosis and viable treatment of fibromyalgia poses difficulties. Fibromyalgia is the second most common issue treated by rheumatologists, though a study Leventhal (1999) revealed that of those patients accepting treatment, under half experienced adequate help with the side effects of FMS. Pharmacological and non-pharmacological approaches that have not appeared to help with a disorder that for a long time was thought to be "all in one's mind" leaves numerous people dissatisfied and unhappy with the current management approaches.

1.4.2. Epidemiology of FMS

Studying the epidemiology of FMS is important for understanding the impact of this disorder on people, families and society. The prevalence of fibromyalgia in the general population of the United States has been reported to be 3.4% in women and 0.5% in men (Wolfe et al., 2010), while the prevalence of FMS in the UK has been reported to be of the order of 2.5% of the population (Longley, 2006). Studies investigating the experience of being diagnosed with FMS reported that 50% to 80% of patients show decline in working memory, attention and executive function (Ablin and Buskila., 2013), with women affected up to 10 times more commonly than men, and with this frequency increasing linearly with age (Sumpton and Moulin., 2008). Furthermore, the prevalence of FMS was found to increase progressively over 80 years of age, before starting to decline. FMS is typically considered to be a disorder that mostly affects women of 20 to 50 years of age; although, it is also found in men, children, and older people.

FMS has been found to be more common in the relatives of patients with FMS, which could be due to the contribution of both environmental and genetic factors. Epidemiological studies have identified that FMS as one of the main causes of CWP. Furthermore, it is estimated that approximately 10% of the general population exhibit CWP complaints, clearly indicating that CWP is a main health problem in the Western world (Queiroz, 2013). Many studies have found higher rates of such complaints

among women compared to men, but the mechanisms responsible for skewed gender rates still remain unclear. FMS therefore represents a major social and economic burden for sufferers, families, and society, with important physical and psychological concerns for individuals. Moreover, it is characterised as a condition in which the central nervous sensitization is manifested by CWP, which is the fundamental symptom of FMS, and widespread tender points (hyperalgesia) (Queiroz, 2013, Azevedo et al., 2012).

1.4.3. Diagnosis of FMS

FMS is a common rheumatological disorder that is a characterized by chronic widespread pain (CWP), the presence of widespread tenderness, and multiple somatic symptoms. Since the publication of the American College of Rheumatology classification criteria for FMS, Wolfe et al. (2010) performed a multicentre study of 829 patients diagnosed with fibromyalgia, where the control group went through physical examinations and interviews, including a widespread pain index (WPI) test, which measures the number of painful body regions. The study found that 25% of fibromyalgia patients did not satisfy the American College of Rheumatology ACR 1990 classification criteria for FMS diagnosis (Giordano et al., 1999).

There are no direct diagnostic investigations, such as X-rays, blood tests, and magnetic resonance image (MRI) scans, for FMS. FMS is an extremely troublesome condition to manage, and there are also other health problems which can be confused with it (Wolfe et al., 1990). In a questionnaire-based trial study conducted with 558 patients, 293 with FMS and 265 control patients, in Canada, FMS patients did not differ statistically from controls in the variables studied (Barker, 2002). However, the study acknowledged that FMS should be diagnosed via a procedure of elimination, which may require several other medical conditions to be ruled out. In the elimination process, blood tests, a complete blood count (CBC), and erythrocyte sedimentation rate (ESR) tests can be performed to exclude other possible diseases such as lupus, anaemia, or polymyalgia rheumatica. In addition, a physical test can be useful for identifying tenderness and rejecting different reasons for muscle pain. Once other conditions have been eliminated, there are two other positive examinations that are generally utilized as part of FMS diagnosis according to the ACR criteria, namely the

widespread pain index (WPI) and the symptom severity score (SS score). The study concluded that a better understanding of the illness' identity is needed.

1.4.3.1. ACR Criteria

The ACR criteria were first developed in the early 1990 , and started a period of increasing acknowledgment of this syndrome (Wolfe et al., 1990). The 1990 ACR criteria for FM diagnosis specified that the pain must be chronic and widespread, defined as axial pain, affecting both sides of the body, above and beneath the waist. Furthermore, the criteria also specified that the patient must have pain in at least 11 out of 18 anatomic sites, known as "tender points", as shown in Figure 1.1, on digital palpitation using a force of about 4 kilograms (kg), and that symptoms must last for no less than three months. These guidelines recommended that primary care physicians should, ideally, promptly recognise and optimally manage FMS (Meyer, 2006). However, in a study conducted in 2010, the 1990 diagnosis criteria were updated to provide an alternative technique of analysis, where the diagnosis of FMS is no longer based on counting the number of tender points. Nevertheless, a full physical examination is still prescribed, alongside other analytic tests to distinguish the indications rather than the aetiology of FMS (Jahan et al., 2012).

The study concluded that well-informed physicians should be able to improve function and reduce pain in patients with fibromyalgia. The reason for excluding the use of tender points for diagnosis is that it became clear that, tender point counts are rarely correctly performed in primary care (Marcus, 2009). (Wolfe et al., 2010, Buskila et al., 1997), As such, in the updated diagnostic criteria of 2010, all other characteristic features of FMS, such as symptoms of fatigue, sleep disturbance, and cognition problems were taken into consideration, and the tender points were replaced with the WPI and the SS test score (Wolfe et al., 2010).

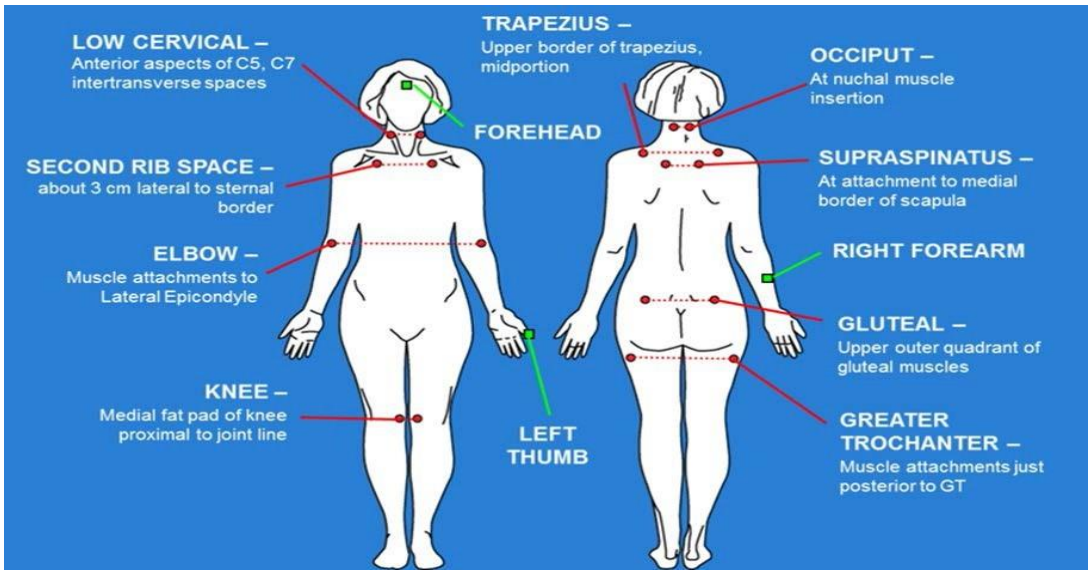

Figure: 1. 1.The tender points based on the 1990 ACR criteria for FMS diagnosis. The red dots indicate the 18 tender points.

1.4.3.2. WPI/SS Test Scores

The modified 1990 criteria for FMS diagnosis now utilise another method in place of tender points count, which incorporates the WPI and SS test scores (Jahan et al., 2012). WPI comprises a total of 19 predefined body areas, and the score represents the number of painful areas in which the patient has experienced pain in the previous 14 days (scoring 0-19) (Wolfe et al., 2010). In the SS test (scoring 0-12), the severity level over the 14 days period is noted for the following three features: fatigue, waking unrefreshed and cognitive symptoms, as shown in Table 1.2. The severity level is rated on a Likert scale from 0 to 3, where 0 represents no problem, and 3 represents a severe problem. The extent of somatic symptoms in general is also noted in the SS scale, and is scored from 0 to 3, where 0 means no symptoms, and 3 indicates a great number of symptoms (Wolfe et al., 2010). Given the scores from the WPI and SS tests, the criteria for FMS diagnosis were developed as follows:

- WPI score of at least 7 and SS score of at least 5, or WPI 3–6 and SS $\geq$ 9.
- Symptoms have been present at a similar level for at least three months.
- No other diagnosable disorder otherwise explains the pain.

Table 1. 2: Main associated symptoms of FMS disease.

Fatigue	Waking unrefreshed	Cognitive symptoms
0 = No problem	0 = No problem	0 = No problem
1 = Slight or mild problems; Generally mild or intermittent 2 = Moderate; considerable	1 = Slight or mild problems; Generally mild or intermittent 2 = Moderate; considerable	1 = Slight or mild problems; Generally mild or intermittent 2 = Moderate; considerable
Problems; often present and/or at a moderate level 3 = severe: pervasive,	Problems; often present and/or at a moderate level 3 = severe: pervasive,	Problems; often present and/or at a moderate level 3 = severe: pervasive,
continuous, Life disturbing	continuous, Life disturbing problems	continuous, Life disturbing problems

1.4.3.3. Labelling of FMS

There have been a series of debates regarding the diagnosis of FMS, and thus the labelling of FMS (White et al., 2002). In the London Fibromyalgia Epidemiology Study, a hundred individuals with FMS were identified. A Fibromyalgia Impact Questionnaire was used to measure their health status and function, and paired t-tests were used in analysing the data. A lack of a clear definition of the condition reported and the absence of clinical outcomes can be applied as FMS labels, as well as fluctuating influences on the long-term condition. Different assessments were utilised, which affected the labelling of the condition to variable degrees. In a review study by Hadler (2003), 22 surveys conducted in the USA were considered, and it was suggested that the diagnostic label of FMS medicalises symptoms, therefore promoting an increase in symptoms, as well as excessive somatic concerns. However, another study found that the FMS diagnostic label did not have a negative influence on clinical outcomes (White et al., 2002).

The health care of FMS patients was compared before diagnosis and pre-labelling, and after diagnosis and post-labelling by Gelfand (2003). In a general population survey in London, Ontario, Canada, of a hundred non-institutionalized adults who met the 1990 American College of Rheumatology criteria for fibromyalgia, it was found that recently diagnosed cases were satisfied with their health. No differences in health service post-labelling were found. There are guidelines that recommend that the diagnostic label of patients with FMS should be linked to their post primary diagnosis. It is also recommended that patients with FMS should be provided with clear information regarding the nature of the disease, strategy, planned treatment, and

expected outcomes., Fitzcharles et al., 2013d and Häusera et al., 2010).A recommended that t the clinical diagnosis of FMS without any defining physical abnormality or biological marker are characterised by fluctuating, diffuse body pain and the frequent symptoms of sleep disturbance, fatigue and cognitive changees.in the absence of cause or cure ,treatment. In a systematic review of n=4 RCTs , guidelines including the American National Guidelines and those from Canada, Germany, and Israel, assessed by two independent reviewers in terms of guidelines inclusion criteria and recommendations,it was highlighted that both The American Pain Society (APS) and Association of the Scientific Medical Societiesin Germany (AWMF) assigned the highest level of recommendation to aerobic exercise, cognitive-behavioral therapy, amitriptyline, and multicomponent treatment. The APS and AWMF guidelines assigned higher ratings to CBT and multicomponent treatments.

In the Israeli guidelines, it was reported that the consensus was that patients with FMS should have knowledge of a biopsychosocial model for fibromyalgia, whereby biological factors such as genetic predispositions, and psychosocial factors such as stress, contribute to the predisposition, triggering and perpetuation of FMS symptoms, including reduction of anxiety, often associated with chronic pain (Ablin and Buskila., 2013). The Canadian guidelines established an extreme attention to prompting events such as physical or psychological traumatic events that may compromise patients' care (Hauser et al., 2012a). On the other hand, the German guidelines implied that accurate information could be valuable in the education of patients, and could help them manage their condition.

1.4.4. Etiology and Pathophysiology of FMS

Aetiology and pathophysiology of the condition is uncertain (Sarzi-Puttini. et al., 2011). The pathophysiology of FMS involves a number of factors, such as abnormalities in the neuroendocrine and autonomic nervous systems, genetic factors, environmental stressors, and psychosocial variables (Bradley, 2009a). Furthermore, the pathophysiology of FMS provides a unique and complex set of challenges, starting with the nosology of the disorder. The development of FMS is possibly due to irregular central pain processing, rather than a dysfunction in the peripheral tissues where such pain is apparent. Several mechanisms may be involved, such as central sensitization, the suppression of descending inhibitory pathways, excessive activity of glial cells,

and abnormalities in neurotransmitter release or regulatory proteins or both. In addition, these mechanisms are probably not mutually exclusive.

Significant progress has been made over the recent decades regarding the aetiology and pathogenesis of FMS, although, neither has yet to be fully understood. A review study highlighted that a number of factors are important for understanding the nature of FMS, such as the autonomic nervous system and dysfunctions of the central nervous system, neurotransmitters, and the immune system, as well as external stressors and psychiatric and hormonal factors (Bellato et al., 2012). FMS is part of a family of associated disorders known as affective spectrum disorders (ASD), which ordinarily co-occur in individuals and co-aggregate in families. These disorders are partly caused by genetic factors, and physiological abnormalities can be central to their aetiology. Moreover, these factors are involved in other disorders that commonly co-occur with FMS, and are also described in terms of persistent or recurrent pain and emotional distress, such as the temporomandibular disorder (TMD), and anxiety disorders. FMS can also occur at the same time as chronic inflammatory diseases, such as systemic lupus erythematosus, osteoarthritis, and rheumatoid arthritis (RA). The presence of one or more of these co-occurring factors can complicate the diagnosis and treatment of FMS.

1.4. 5. Co-morbid Factors of FMS

Co-morbid factors are involved in other disorders that commonly co-occur with FMS, and which are also characterized by persistent or recurrent pain and emotional distress, such as temporomandibular disorder (TMD), and anxiety disorders. A structured clinical interview of 108 individuals with fibromyalgia compared with 228 individuals without fibromyalgia concluded that there is a possibility that fibromyalgia might share underlying pathophysiological links with certain psychiatric disorders. (Arnold et al., 2006). A retrospective cohort study of a claims database examined the international classification of diseases. The study reported that FMS could also occur at the same time as chronic inflammatory diseases, such as systemic lupus erythematosus, osteoarthritis, and rheumatoid arthritis (RA) (Weir et al., 2006).

1.4.6. Central Nervous System (CNS) Sensitization in FMS

Central sensitization plays a critical role in the mechanism of FMS, and can be described in terms of an enlarged response to stimulation mediated via CNS signalling. In a self-administrated questionnaire conducted with n=103 patients, data was gathered using a Minnesota Multiphasic Personality Inventory (MMPI), and analysed using SPSS. The participants were recruited from an outpatient rheumatology clinic, and the study concluded that pain severity may be influenced by physiological and psychological actors (Yunus. et al., 1991). A review by (Staud, 2009) demonstrated that FMS patients showed psychophysical indications of mechanical, thermal, and electrical hyperalgesia. A number of earlier empirical studies of FMS demonstrated CNS pain processing abnormalities, such as the abnormal temporal summation of pain (Staud and Spaeth., 2008).

Thus, a central sensitization abnormality of nociception has been defined in fibromyalgia. Vital nociceptor systems in the skin and muscles appear to undergo changes in FMS patients (Staud and Smitherman., 2002). This phenomenon, termed "wind-up", appears as one main mechanism that reflects the increased excitability of spinal cord neurons after a painful stimulus, where subsequent stimuli of the same intensity are perceived as stronger (Kindler et al., 2011). This happens normally in everyone, but it is extreme in FMS patients. These findings indicate both an increased and a prolonged decay of nociceptive contribution in FMS patients, which provides strong evidence for the role of central sensitization in the pathogenesis of FMS (Gur and Oktayoglu., 2008). A better understanding of these mechanisms and their relationship to central sensitization and clinical pain may allow the development of novel methods for the prevention and treatment of FMS symptoms (Gur and Oktayoglu., 2008).

1.4. 7. The Neuroendocrine System and FMS

FMS is commonly considered to be a stress-associated disorder that includes abnormal functioning in the hypothalamic pituitary adrenal (HPA) axis (Bradley, 2009a, Staud, 2007). The HPA axis plays a main role in the control of responses to stress. Human stress associated with conditions such as FMS, chronic fatigue syndrome(CFS),and post-traumatic stress disorder are characterized via changes in HPA axis activity

(Becker and Schweinhardt., 2012). The HPA axis is altered in FMS (Williams and Clauw., 2009), although the consequences of the specific alterations are heterogeneous. In both the central nervous system (CNS) and the autonomic nervous system (ANS) , hyper and hypo-activity in basal functioning and acute stress responses have been reported (Martinez-Lavin, 2007).

It has been found that stress-related conditions increase the risk of developing FMS, depending on different susceptibility factors, such as genetic make-up and gender (Staud, 2007). However, it is still uncertain which physiological developments mediate the relationship between stress and the development of FMS. Alterations in the HPA stress systems are often considered to be such mediators, with chronic stress exposure changing the function of this stress system, thereby producing FMS symptoms (Staud, 2007); (Schweinhardt et al., 2008, McVeigh et al., 2007). From this viewpoint, the basic symptom of the condition appears to be associated with changes in the HPA axis.

In addition, it has been reported that the levels of clinical pain can be considered to be related to the concentrations of corticotropin-releasing hormone (CRH) in the cerebrospinal fluid (CSF), and the salivary cortisol level (McLean et al., 2006). The endocrine system is a vital interface for responding to pathological developments such as inflammation, emotions, and to behavioural changes such as physical exercise (McLean et al., 2005). Studies of HPA axis functioning in FMS have, on average, shown normal basal levels, such as urinary free cortisol and normal salivary cortisol levels (Geenen et al., 2002). However, a study of the dynamic functioning of the HPA axis in response to psychological, physical, and pharmacological challenges identified variations from normal functioning (Griep et al., 1993). This study showed an exaggerated corticotrophin (ACTH) response to the exogenous corticotrophin-releasing hormone (CRH) neurons, as a result of the upregulation of pituitary CRH receptors in FMS.

Numerous studies have also shown that stress-related disorders are characterized by HPA dysfunction. It has also been found that hypocortisolemia is most commonly the main neuroendocrine abnormality. However, data is still inadequate to allow clarification of the pathophysiology of HPA dysfunction, the location of the defect, and the exact role of the hypocortisolemia in patients with stress. Whether this plays

a role in the progress of stress-related conditions, or happens through the natural history of FMS disorder (Tanriverdi et al., 2007) has yet to be elucidated.

1.4.8. Autonomic Nervous System (ANS) and FMS

FMS is observed in patients with autoimmune diseases, and can be a source of many of the symptoms of disability exhibited in these patients (Buskila, 2009) Abnormalities in autonomic nervous system (ANS) functions are often seen in FMS patients. Over the last decade, reports of ANS dysfunction in the aetiopathogenesis of FMS have increased, which may help explain the symptomatology and psychological and physical features found in patients with FMS (Buskila, 2009). The role of autonomic and immune factors, and their relationship to other conditions might provide information regarding the pathophysiology of FMS. Although FMS has been found not to be associated with systemic lupus erythematosus disease activity, the clinical characteristics of FMS can contribute to the misconstruction of lupus activity in FMS patients (Buskila and Sarzi-Puttini, 2008). A widespread pain can be enhanced and triggered by pain related to arthritis and autoimmune diseases, and generate a peripheral nerve pain in both neck and back regions (Buskila, 2009). Thus, there is a considerable overlap between symptoms, which may suggest similar mechanisms are behind the development of these symptoms.

1.4.9. Sleep Disturbance in FMS

FMS is often considered to be related to sleep disturbance, characterized by the experience of non-restorative sleep (Bradley, 2009a). The most common of complaints concerning sleep disruption are associated with polysomnographic features, with strong abnormalities seen in the continuity and architecture of sleep. Abnormal sleep recordings are characterised by the diminished efficiency of sleep, with increased numbers of awakenings. Furthermore, thy are also characterised by a decrease in the amount of slow wave sleep, and an abnormal alpha wave intrusion in the non-rapid eye movement, which is termed alpha-delta sleep (Dauvilliers and Touchon, 2001). In polysomnographic studies, alpha-delta sleep patterns, correlated to interrupted and non-restorative sleep, have often been observed in FMS patients (Dauvilliers and Touchon, 2001). Sleep disturbance can be linked to the decrease in energy and fatigue frequently found in FMS patients (Bradley, 2009a). Data on the distribution of sleep

types may provide new evidence on sleep fragmentation. Currently, the analysis of data has shown that periods of nocturnal sleep and waking may be categorized via different statistical distributions in healthy individuals (Arnardóttir et al., 2010).

1.4.10. Genetic Factors in FMS

Based on incidences of FMS in families, several investigations have found that genetic factors can be associated with a predisposition to FMS, in combination with environmental triggers, such as infections and trauma. Hypothetically, the main gene polymorphisms which can be a risk factor for FMS are those associated with mood conditions, but such assumptions are frequently debatable (Cohen et al., 2002). Recent reports have stated that genetic factors can play a role in the pathogenesis of FMS, including serotoninergic receptors such as 5-HT2A, and polymorphisms in the T/T phenotype, such as the SLC6A4 serotonin transporter (Buskila, 2009) .

Some studies have shown a role for gene polymorphisms in the serotoninergic, dopaminergic and catecholaminergic systems in the etiology of FMS (Buskila, 2009). Polymorphisms in the serotonin 5-HT2A receptor (T/T phenotype), serotonin transporter, and in the dopamine 4 receptor have hence been identified at the highest incidences in FMS patients (Buskila and Sarzi-Puttini, 2008). Moreover, environmental factors have been found to trigger the progress of FMS in genetically inclined individuals (Buskila, 2009).

1.411. Environmental Trigger Factors in FMS

In addition to the association of genetic factors with the pathophysiology of FMS, environmental trigger factors might also be involved, particularly in combination with other risk factors. These trigger factors include physical trauma, injury, and psychosocial stressors (Al-Allaf et al., 2002). Furthermore, these may arise from manual work, such as repetitive motions or squatting for extended periods of time, which have been fundamentally connected with the onset of several musculoskeletal pain disorders, including widespread pain (Harkness et al., 2004). In addition, other environmental factors like working in hot conditions have also been found to increase the risk of developing widespread pain (Bradley, 2009a). A study by Davis et al. (2001) conducted a questionnaire-based survey of 50 participants with FMS, recruited from community seminars. The survey included a screening instrument, a pain-coping

inventory, and measures of personality dispositions.

Cross-sectional analyses were employed, and it was reported that exposure to short-term psychosocial stressor factors increased people's symptoms, and may be linked with FMS. Thus, it can be seen that there are a variety of issues involving a range of pathophysiological mechanisms, with concomitant and consequent sequelae that may impact upon the physical and emotional experience of this condition. In addition, controversies and discrepant diagnoses by health professionals also affect the subsequent management and experience of health care, and health care seeking by patients. The next section discuses current management approaches to the condition.

1.4.12. Management and Treatment Approaches of FMS

Because of its unidentified aetiology and vague pathogenesis, there is as yet no standard treatment that can completely cure FMS. The treatment of FMS is mainly focused on the management of the disease to reduce the severity of symptoms (Marcus, 2009, Staud, 2007). A previous review by Ablin and Buskila. (2013) attempted to summarise the therapeutic advances and future directions in the management of FMS, and reported that improvements in the understanding of the pathophysiology of FMS have prompted changes in treatment, incorporating management using various pharmacological and non-pharmacological approaches, including complementary and alternative modes of management. There is evidence that non-pharmacological treatments, including cognitive behavioural therapy (CBT) and exercise, are effective in the management of FMS (Sim and Adams., 2002). This systematic review of 25 RCTs, reported upon the evidence for non-pharmacological interventions. In a recent study, an RCT of 56 subjects in an outpatient rheumatology clinic were used to assess the effect of internet-based CBT on FIQ and tender point assessment. It was concluded that internet-based CBT could be beneficial in the treatment of FMS (Menga et al., 2014).

EULAR recommendations made by 19 FMS experts representing 11 European countries showed that there are other types of FMS non-pharmacological treatments used singly or in combinations, including physical therapy, massage therapy, acupuncture, homeopathy, dietary, and osteopathic manipulation (Carville et al., 2008a). Furthermore, it was found that patients' education, and spa therapy are also

used, and the study concluded that no guidelines exist for the management of FMS.

There is some evidence of the effectiveness of multicomponent treatment, including pharmacology, and non –pharmacological approaches, such as aerobic activity and cognitive behavioural treatment, in reducing pain and other FMS-associated symptoms (Hauser et al., 2009, Sim and Adams., 2002). Based on meta-analyses, up to 90% of people suffering from FMS have utilized at least one type of pharmacological or alternative treatment to deal with the symptoms caused by FMS (Ernst, 2008). Another review study of the use of complementary or alternative medicine (CAM) interventions to treat and manage FMS symptoms, considered five systematic reviews in an evaluation of interventions. It was found that there were some beneficial effects of acupuncture, homoeopathy and hydrotherapy, whilst no therapeutic effects were discerned from chiropractic interventions for the treatment of FMS symptoms (Terry et al., 2012). However, for the majority of patients, pharmacological management remains the mainstay of therapy for FMS.

In recent years, a number of recommendations have been published by several organizations, including the European League Against Rheumatism (EULAR) (Carville et al., 2008a), the Association of the Scientific Medical Societies in Germany (AWMF) (Winkelmann et al., 2012). The Canadian Pain Society (CPS) (Fitzcharles et al., 2013d), and the American Pain Society (APS) (Burckhardt et al., 2005), in an effort to standardize the treatment of FMS. These organizations have provided evidence-based recommendations related to the evaluation and diagnosis of FMS, and the non-pharmacological and pharmacological therapies that can be used in its management. A comparison of these guidelines showing the strongest recommendations from each organization is presented in Table 1.3.

1.4.13. Pharmacological Approaches to FMS

Analysis of the results of pharmacological management of FMS have shown equivocal findings, with some medications appearing to provide relief of some symptoms for some patients, but not for numerous others. Pharmacological agents influencing the central nervous system are thought to be the best pharmacological treatment of FMS. Decreasing pain in people with FMS is the essential objective of most drugs that aim to offer patients some assistance in coping better with their

condition.(Mease et al., 2011, Goldenberg et al., 2008).

A RCT study of pregabalin conducted on 3808 patients with FMS found that a minority of patients achieve moderate or substantial pain relief. Beside pain centred therapies, drugs can be prescribed to target sleep issues and fatigue, as well as the possible side effects of co-existing conditions, such as irritable bowel syndrome, bladder distress, jaw pain, and headaches and migraines. Thus, drugs must be individualized according to patients' symptoms (Straube et al., 2010).

1.4.14. Pain-treating Drugs in FMS

Around 20 to 40% of patients with FMS experience depression. The regular comorbidity of FMS with depression supports the utilization of antidepressant drugs for FMS (Goldenberg et al., 2004, Bennett, 2005), which can be used to treat mood, sleep and pain symptoms. They act on neurotransmitters to make them reduce or slow down pain-related messages (Marangell et al., 2011). Such drugs include amitriptyline and doxepin, as well as the selective serotonin reuptake inhibitors (SSRIs), duloxetine and milnacipran (Hauser et al., 2009). The objective of antidepressants is to reduce symptoms, and if utilised long term, their effects should be evaluated against symptoms. Some benefits have been reported with the use of duloxetine, milnacipran and amitriptyline; however, numerous individuals encounter more unfavourable impacts than benefits. A recent systematic review and meta-analysis designed in the form of a randomized controlled trial (RCT) of antidepressants in FMS patients with pharmacological placebo was conducted and included thirty-seven studies. It was concluded that physicians and patients should be realistic about the potential benefits of using antidepressants in treating FMS symptoms (Hauser et al., 2012b). A UK study used RCTs with double-blind assessment of outcomes of five studies and included 4138 participants, where two authors examined issues of study quality independently. It was found that amitriptyline has been prescribed as a first-line treatment, but the evidence to support this utilisation is poor (Derry et al., 2012).

Anti-epileptic drugs such as pregabalin and neurontin are also used for FMS treatment, as reported by a US review paper (Bennett, 2005), with varying degrees of success. USA-based RCTs showed that treatment for muscle tension and pain may incorporate a prescription for a muscle relaxant drug, such as Xanaflex (tizanidine) or Flexeril

(cyclobenzaprine) (Holman and Myers., 2005).

Tramadol is another widely used analgesic that has a unique mechanism of action. Tramadol is the mildest of all opioids, and has been observed to be useful in patients with FMS (Bennett, 2005). It is an atypical pain reliever, in that has an alternate mode of activity compared to other opiates, as it boosts the action of serotonin and norepinephrine to higher levels than those of other opiates, to help further lessen anxiety. Alone or in combination with acetaminophen, it is normally recommended at a dose of 200–300 mg/day to diminish FMS-related pain. However, RCTs results suggested that there is a hypothetical danger of seizures and serotoninergic disorders when tramadol is combined with specific SSRIs (Holman and Myers., 2005). On the other hand, tramadol combined with paracetamol is considered to be a compelling and all-around effective treatment for fibromyalgia (Moron Merchante et al., 2013). A previous review paper reported that opioids are also used for treating severe pain in patients with FMS, despite a lack of clinical trials in the USA (Nersesyan and Slavin., 2007). Another review study highlighted that these drugs are not suggested by any present guidelines for the treatment of patients with FMS, as they might worsen symptoms such as fatigue and cognitive impairment (Bellato et al., 2012).

Insomnia is a major issue in individuals with FMS. Studies have shown that continuous sleep disturbance inhibit the growth hormone, which is a critical restorative hormone, from being created by the body (Boomershine and Crofford., 2009). Without this hormone, muscles cannot completely recuperate, and neurotransmitters, such as serotonin, are not replenished. A cross-sectional study enrolled 172 patients with FMS and found that people with insomnia are often given medications such as Ambien (zolpidem),Lunesta (eszipoclone), or trazodone, to help them improve their non-restorative sleep quality (Viola-Saltzman et al., 2010).

Fatigue is considered as the second worst symptom after pain in patients with FMS. This issue is more serious than what individuals consider to be conventional tiredness, and strongly affects the quality of life. Fatigue can be due to a reduced thyroid hormone, and it has been shown that 30% of patients with FMS commonly experience extreme fatigue (Bazzichi et al., 2007).

1.4.15. Multidimensional Approach to Management

There have been a number of pharmacological advances in the management of FMS, many of which are used to control the symptoms.

From the guidelines, it is apparent that pharmacological therapy plays a significant role in the management of symptoms, however, many of the side-effects are not tolerated well by patients. Thus, a multidimensional, multidisciplinary approach is necessary to treat the various aspects of this condition. There is promising evidence for the use of non-pharmacological approaches as part of a multidisciplinary approach. These approaches are reviewed below.

Table 1.3 shows a comparison of guidelines from four organisations, indicating the strongest recommendations from each. The information in this table was taken from.(Fitzcharles et al., 2013a, Winkelmann et al., 2012, Burckhardt et al., 2005).

Table 1. 3: Recommendations for Management of FMS

American Pain Society (2005)	European League Against Rheumatism (2008)	German (2012)	Canadian Pain Society (2013)
Tricyclic. Antidepressants: Amitriptyline. Cyclobenzaprine. Aerobic exercise. Cognitive behaviour therapy (CBT). Multicomponent therapy	Tramadol. Antidepressants: amitriptyline, fluoxetine, duloxetine, milnacipran Pregabalin or pramipexole Aerobic exercise, CBT and multicomponent therapy	Aerobic exercise. Cognitive behaviour therapy (CBT). Antidepressants. Multicomponent therapy	Tricyclic. Antidepressants Serotonin norepinephrine reuptake inhibitors Selective serotonin. Reuptake inhibitors. Anticonvulsants. Cognitive behaviour therapy (CBT). Multimodal approach to treatment. Interventions that improve self-efficacy. Graduated exercise program.

Many patients utilise non-pharmacological approaches, including complementary treatments. Surveys have demonstrated that 91% of patients with FMS utilised non-pharmacological treatments to manage the symptoms of FMS, with 66% utilising more than one complementary treatment. A survey study administered an interviewer-based questionnaire to 221 consecutive rheumatology patients and 80 FMS patients, and reported that alternative medicine was being used by FMS patients (Pioro-Boisset et al., 1996). (Adams and Sim, 2005). Such alternative therapies included holistic

movement therapy, energy therapy, balneotherapy, and osteopathic and chiropractic manipulation. As previously stated, treatment approaches are rarely standardised, and

at breaking the cycle between symptoms and patterns of dysfunctional performance (White, 2001). Techniques incorporated include relaxation, sleep hygiene, the pacing there is a heterogeneity of exercise programmes. In addition, there are few UK-based intervention studies, which may be due to the difficulty in defining a standard treatment, resulting in high variability between the usual treatments. Thus, despite the European guidelines on the recommendations of interventional approaches, there is no standard treatment approach for fibromyalgia in the UK, with considerable variation in the provision and availability of services. An earlier questionnaire-based study (Sim and Adams, 2003b) surveyed the physiotherapeutic management of FMS, although rheumatology and pain management clinics were not surveyed. Therefore, one aim of this research is to update this previous study, and describe the current clinical practice in the UK. This thus forms one phase of this research.

1.4.16. Cognitive Behaviour Therapy (CBT)

CBT has been extensively studied as a non-drug intervention for FMS. In a randomized study of n=58 patients with FMS (Ang et al., 2013), the participants underwent a combination therapy including milancipran, education, placebo and CBT. CBT which is frequently incorporated into multidisciplinary pain management programmes, had moderate effect on improving physical function and reducing pain compared to milnacipran, CBT is a composite of two methodologies; cognitive treatment, and behavioural treatment (White, 2001). It is a form of psychotherapy that mainly focuses on the understanding of how the patients' thoughts and emotions may contribute to the dysfunctional negative thoughts and behaviours, and has been broadly used to treat depression and anxiety. An RCT-based study involved 56 subjects undertaking an internet-based CBT, using the Fibromyalgia Impact Questionnaire (FIQ) as an outcome measure found no significant difference in the FIQ scores in both groups. (Menga et al., 2014).

The fundamental aims of CBT are twofold: first, the recognition of and change to the dysfunctional thought patterns that are interfering with therapeutic progress; and secondly, the engagement of the individual in behavioural interventions aimed of

activity, scheduling social and leisure activities, coping with pain, education, and assertiveness training (Williams, 2003). In a RCTs-based study by Nielson et al (1992), a total of 131 patients with FMS were randomly selected. Data was analysed by a standard rating scale, and the results showed significant improvements in patients who accepted CBT with respect to pain severity and the number of pain-related behaviours (Nielson et al., 1992).

In addition, a US review study demonstrated that CBT for FMS patients can improve pain, fatigue, and function (Williams, 2003). In contrast, a review of RCTs in Netherlands reported that limited change was seen in pain and mood from six randomized controlled trials, and that the use of CBTs within a multi-component approach yielded the most benefits (Koulil et al., 2007). In addition, a systematic review and meta-analysis of six trials (Lauche. et al., 2013) reported low quality evidence for short term improvement of quality of life. In a UK review paper providing an overview of published evidence for interventions in FMS (Adams and Sim, 2005), it was concluded that CBT interventions have proven useful in the treatment of FMS as part of multicomponent treatment. Different studies have used contrasting classifications and techniques of CBT within their programmes, normally as part of multimodal programmes that combine CBT with physical exercise rather than through CBT alone. In clinical practice, multimodal FMS treatment programmes with a combination approach are widely encouraged and have received some support from a systematic review (Sim and Adams., 2002). Despite evidence for the effectiveness of these interventions, and particularly exercise, patients still report dissatisfaction, and the use of these interventions have high dropout rates. The reasons for this are explored in this research.

1.4.17. Physical Therapy Approaches and Exercise Rehabilitation

A recent systematic review and meta-analysis of sixty randomised controlled trials (Sosa-Reina et al., 2017) concluded that aerobic and muscle strengthening exercises are the most effective ways of reducing pain, and improving the general well-being in people with fibromyalgia. In addition, combined exercise produced the most beneficial effect on symptoms of depression. Only one of these RCTs was conducted in the UK (Richards and Scott., 2002), and most trials used the Fibromyalgia Impact Questionnaire (FIQ) as an outcome measure to assess pain, depression, physical and

functional impact of fibromyalgia, and the general well-being (FIQ total score).

Although this meta-analysis considered previous systematic reviews and meta-analyses (Hauser et al., 2010, Kelley et al., 2010), it was not able to draw conclusions about type, dose and duration of exercise, as few studies included such details. Adherence to exercise regimes was also an important issue that has been identified from reviews, and requires further investigation. Thus, one aim of this research is to identify whether physical and behavioural approaches are routinely used in UK practice, and the views of people with fibromyalgia regarding their participation in these approaches.

A randomized controlled trial of 130 women with FM (Larsson et al., 2015) concluded that resistance exercise was found to be a feasible mode of exercise for women with FM, improving muscle strength, health status, and current pain intensity. Recently, an assessor-blinded randomized controlled multicentre trial of 130 women with FM (Ericsson et al., 2016) examined the effect of resistance exercise compared with active exercise. The study showed that person-centred progressive resistance exercise contributed to improvements in physical fatigue in women with FM. In addition, a randomized controlled trial of eight women with FM, who completed the FIQ and a short-form health survey (SF-36), and were selected for controlled trials of straightening exercises, (Oliveira Gavi et al., 2014), concluded that strengthening exercises show greater and more rapid improvements in pain and strength than flexibility exercises.

Aerobic exercises such as walking, cycling, dancing, pool exercises, and tai-chi are regularly prescribed, and it has been demonstrated that low or moderate intensity exercises are more successful in reducing the symptoms of FMS (Busch et al., 2011, Alentorn-Geli et al., 2008). It is understood that exercise adjusts inflammatory reactions through neuroendocrine components. Since FMS disorder is by all accounts related to a deregulation of the inflammatory reaction, it could be conceivable that exercise treatments could work at this level in FMS patients (Ortega et al., 2009).

Exercise is therefore an important part of managing FMS, though what is less well known is the dose, duration and frequency of exercise required. In addition, many patients drop out of exercise programmes, the reasons for which are explored in this

research study.

1.4.18. Massage Therapy (MT)

Massage therapy (MT) can have immediate beneficial effects on improving pain, anxiety, and depression in patients with FM. A systematic review of nine randomized controlled trials involving 404 patients (Li et al., 2014) recommended that massage therapy should be one of the viable complementary and alternative treatments for FM.

MT has been broadly utilised by up to 70% of patients suffering from FMS and seeking symptom relief (Wahner-Roedler et al., 2005). It is claimed that massage can reduce pain and muscle tension, improve the mood, and reduce sleep disturbance, via a complex interplay of both physical and psychological modes of action (Moyer et al., 2004).

Some studies have shown that massage therapy can be helpful in the management of FMS. Single-arm studies have shown significant short-term benefits in improving restorative sleep, and reducing fatigue and stiffness in patients with FMS (Field et al., 2002).

In addition, one study found sustained improvements in pain and sleep after patients were given MT sessions for about 6 months. After a one-year follow-up assessing the impact of a combined massage and ultrasound treatment, another study showed significant improvements in pain intensity, and function, and a reduction in complaints of non-restorative sleep (Citak-Karakaya et al., 2006). Nevertheless, these outcomes must be treated with caution, as in studies that exclude a control group placebo effects and spontaneous improvements in FMS symptoms cannot be eliminated. In contrast, no benefit of MT was found in a study performed by Alnigenis et al. (2001). However, this could be due to the low quality of the methodology used and the small sample size. In addition, in all of the studies cited above, the type of massage used was not specified. A review paper by Hardy-Pickerin et al. (2007) reported that massage therapy was often a popular choice with patients, despite limited research evidence for its effectiveness. The reasons for this are also explored in this research.

1.4.19. Spa Treatment

Spa treatment covers a wide range of modalities, including hydrotherapy, balneotherapy, physiotherapy, mud-pack treatment, and exercise. A review conducted by Fioravanti et al. (2011) on mechanisms of thermal water and the application of mud, found that such techniques alleviate suffering in rheumatic diseases . The study concluded that the beneficial effects of spa therapy in some rheumatic diseases include changes in the environment, pleasant surroundings, and the absence of work duties. Spa treatment is a popular treatment for FMS in numerous European nations and Japan. A review study by (Guidelli et al., 2012) concluded that spa therapy can represent a useful back-up to pharmacological treatment of FMS, or be a valid alternative for patients who do not tolerate pharmacological treatments. However, in spite of their long history, spa medications are still a subject of controversy, and their part in cutting edge prescription is still not clear due to the lack of controlled trials and the heterogeneity of the treatment (Guidelli et al., 2012).

1.4.20. Coping Strategies in FMS

Coping with FMS may be difficult due to the chronic nature of the condition and the reported 'invisibility' of symptoms. Coping strategies are a key element of any pain management programme and of cognitive-behavioural therapy, and are designed to assist the patient to better manage their pain and other symptoms. It has been suggested that FMS is a functional and psychological condition, and that symptoms are due to the somatization of stress (Gupta and Silman, 2004). In a descriptive study of 20 women with FMS (Homann et al., 2012), health assessment questionnaire, fibromyalgia impact questionnaire, and visual analogue scale were used. The study reported that psychological factors and dysfunction seem to be part of a complex mechanism, which might affect the quality of life of patients with FM and exacerbates the symptoms. Several theories imply that traumatic psychological factors discussed in earlier section of review and environmental factors are causes of FMS, and that it can, in part, be explained by neuroendocrine and CNS disturbances and responses to these factors.

A number of studies have reported that coping with pain and other FMS symptoms is the main objective in managing FMS. Coping is defined as the way in which a person

attempts to modify adverse aspects of their environment and stress (Jones et al., 2010). Although there is no single universally accepted definition of coping, there appears to be an emerging consensus among theoreticians, clinicians and researchers alike, that coping styles constitute an important component of the individual's adaptation to the impact of different stressors, including extreme psychological trauma. It seems that it is not the stressor alone that leads to a serious outcome, but the way in which a person perceives and responds to it (Horesh et al., 1996).

As there are no medications to eliminate FMS symptoms, the symptoms need to be coped with and managed by both patients and health professionals. Based on current evidence, a coping strategy is likely to include the reduction of stress, patient education, and physical strategies such as exercise.

1.4.21. Reduction of Stress

There are various theories which state that stress can play a critical role in triggering FMS symptoms (Schmidt et al., 2011), although whether this is aetiological or a result of the pain, fatigue and consequent reduced function, is unclear (Adams et al., 2006). However, there are a number of people with FMS who experience psychological symptoms such as anxiety and depression, and these are exacerbated around the time when FMS symptoms flare up (Glass et al., 2005). A systematic review and meta-analysis of six randomized controlled trials (RCTs) with a total of 674 FMS patients (Lauche et al., 2013) used mindfulness-based stress reduction (MBSR) to treat fibromyalgia. Outcome measures were quality of life (QOL) and pain, including sleep quality, fatigue, depression and safety, and only minimal changes were found in pain, quality of life, depression and anxiety.

1.4.22. Communication

Communication is also important in a chronic disease such as FMS. A descriptive study used a questionnaire to survey n=254 FMS participants, and the descriptive parameters were calculated. (Ullrich et al., 2014), and concluded that service providers who communicate with FMS patients should employ an open and patient-centred communication style. Moreover, psychological variables were identified in all communication preferences, the ability of the health care professional to engage in effective communication can create a positive therapeutic alliance and encourage

behaviours to optimize the patient's capacity to live as fully as possible with that specific illness. A survey study by Farin. et al. (2013) conducted on n=701 patients with chronic low back pain found that communication is very important for patients with chronic pain especially for communication about emotional and FMS conditions.

From previous studies, it is known that people with fibromyalgia feel that they are not understood, and that health professionals are not well informed about their condition (Sim and Adams, 2003b), in contrast to the views of health professionals themselves. The importance of good communication cannot therefore be underestimated.

1.4.23. Assessing the Impact of Fibromyalgia in Patients' Daily Living.

FIQ is a commonly used instrument in the diagnosis of FMS patients, and is commonly reported in evaluations of fibromyalgia's impact on functions and daily living activities (Hauser et al., 2009, Sim and Adams., 2002). It is a self-report questionnaire developed to assess the health status of FMS patients (Burckhardt et al., 1991). A previous study conducted by (Rodero et al., 2010) used a 3-item instrument, and focused on patients' capacity to perform functional activities, where two items were used to evaluate patients' feeling, and the number of days of not feeling well or missed work in the past week. The last seven questions estimating the workability, pain, fatigue, morning tiredness, stiffness, and psychological features were assessed with the graphic analogue scale. Whilst a variety of outcome measures have been used in studies of fibromyalgia, these are generally used within RCT designs, and the psychometric instruments used include the Pain Visual Analogue Scale (PVAS) for pain intensity. The Hospital Anxiety and Depression Scale (HADS), the Medical Outcome Study Short Form 36 (SF-36), the Pain Catastrophising Scale (PCS), and the Fibromyalgia Impact Questionnaire (FIQ) are occasionally used. However, none of these captures the in-depth experiences of patients. This research seeks to both record the use of assessment instruments in fibromyalgia by clinicians, as well as capture the in depth and life experiences of patients.

1.4.24. Patients' Experiences of FMS.

A number of studies have found that, despite the scale of the syndrome's influence on their lives, females with FMS felt that their experiences were hidden from nearly

everyone except themselves (Soderberg and Lundman, 2001). Furthermore, individuals with FMS face the quandary of living with a condition that they find to be extremely limiting; while, at the same time, it is 'invisible' to other individuals (Raheim and Haland, 2006). A study by Paulson et al. (2002) conducted narrative interviews with 14 men with fibromyalgia, who were patients in the Swedish health care system, regarding the pain they experienced. Content analysis was used to analyse the data, and it was found that the subjects were struggling to achieve a tolerable existence, and specifically that individuals with FMS experienced basic changes to their social lives and interactions with society overall, which can bring about a decrease in social interaction, and thus, social support in the community. Baanders and Heijmans. (2007) also stated that living with a chronically sick individual affects the partner's own life. A study by Rodham et al. (2010) conducted qualitative semi-structured interviews with 4 women with FMS, aged between 38 and 65, and their spousal carers, who were interviewed separately. The participants all came from the south-west of England. The resulting transcripts were analysed using interpretative phenomenological analysis. More than half of the carers in the study described the strain on their own lives, whereas 20% cited changes in social relations and monetary issues. Although this small sample size limits the transferability of the findings, the participants reported feeling isolated from healthcare professionals, and this sense of isolation was evident for the carers as well as the people with FMS.

A number of studies have centred on the life experience of individuals with FMS, while others have focused on their partners (Soderberg and Lundman, 2001). Considering that life partners form the central social support for patients with FMS, it is important to explore their experience of this burden of caring, and the effect of such burden on their relationships.

1.4.25. Experiences of Being Diagnosed of FMS

The diagnosis of FMS may be difficult, as not only are there no laboratory tests or imaging tests that can recognise the condition, but there are additionally various different conditions that share similar symptoms with FMS. When diagnosed with the condition, patients struggle to find a new identity to deal with the reality of living with a chronic condition, where they are socially identified and self-defined only by their disabled bodies.

Accepting a conclusion can be one of numerous defining moments in the lives of individuals with chronic disabilities (King et al., 2003). Nevertheless, clinical reality does not generally give a conclusion the ability to clarify disease.

A study performed by Steihaug and colleagues (2002) interviewed 24 women who talked about their experiences with chronic pain. Participants were drawn from an action research project using focus group interviews, and data was analysed using Giorgi's principles of phenomenological analysis. The participants described their pain and symptoms as 'limitless', and stated that understanding the experience of living with such pain provided a clarification and acknowledgment of the pain experience. Furthermore, the participants established that recognition had an important effect on how much they benefited from an intervention programme. (Steihaug et al., 2002).

1.4.26. Patient Education.

In a recent randomised controlled clinical study of 66 patients diagnosed with FMS (Kocyigit et al., 2016), a 20-minute long education session on FMS was provided to 2 groups (a balneotherapy group and a control group) at the beginning of the treatment, and patients were evaluated using the FIQ. It was concluded the combination of balneotherapy and patient education has both short- and long-term beneficial effects on patients with fibromyalgia.

In a study of seven women with FMS (Karper, 2016), the subjects attended a university-based programme three days per week, which involved ongoing group education. The patients were evaluated periodically with a fitness test and a rating scale in terms of pain and fatigue. The outcomes showed various positive results from participation in the programme. In another randomised controlled single blind study of 70 women with FMS (Bağdatlı et al., 2015), the subjects were divided into balneotherapy, hydro-pool and control groups. All patients took patient education about FMS and a home exercise programme. Outcome measures were based on FIQ and BDI, and it was concluded that patient education combined with two weeks of balneotherapy had effects that were more beneficial in patients with fibromyalgia compared to patient education alone.

In a qualitative study by Robinson et al. (2016) that used an approach based on interpretive phenomenology analysis (IPA), ten patients with chronic musculoskeletal

pain were recruited from an NHS pain clinic in a hospital in the North East of England. The patients attended a group education session on pain neurophysiology education (PNE), and individual face to-face interviews with the researcher. The majority of the participants reported benefits from the PEN session, whereas a few reported no benefits.

A recent systematic review consisting of a meta-analysis of randomised controlled trials of educational interventions for chronic pain included studies that were RCTs, and which measured pain for more than three months, as well as disability and the effect of education (Geneen et al., 2015), found that, based on a small number of studies, limited evidence was found, and the difference in education levels was reported. It was concluded that education alone is not effective in reducing pain intensity or the associated disability in chronic pain conditions.

Most specialists agree that an instructive or psychoeducational part of treatment is valuable, if not necessary, when treating FMS (Carville et al., 2007). Increasingly, educational programmes have become an important part of understanding the links between neurological procedures and behaviours, such as sleep, activity levels, and symptoms. These programmes have varied foci, but as a rule, attempt to allay the stigma often attached to FMS (Hassett and Gevirtz, 2009). A study by Goldenberg et al. (2008) set out recommendations regarding education that appear well-founded. In addition, it has been pointed that patients education and available information would be discussed the pathophysiological mechanisms of FMS in the bio-psychological context model thus the nature of the illness indicates that psychogenic implications were reported on patients with FMS. Education and behavioural programmes for FMS treatment protocols are necessary, particularly when combined with other modalities such as exercise, sleep hygiene, and activity pacing, using some form of behavioural intervention, and appear to improve the effectiveness of the treatment of FMS (Hassett and Gevirtz, 2009). Patients' experiences of receiving information and education are further explored in this research study.

1.4.27. Emotional Factors in FMS: Alexithymia

Alexithymia has been identified as being widely present and pronounced in FMS patients (Baeza-Velasco et al., 2012). Furthermore, the understanding of the emotional

features and how they are linked to FMS may be challenging due to the personal elements of alexithymia in FMS. The emotional aspects could be linked to different extents of awareness that demonstrate the psychological and theoretical perspectives of people's attitudes; including listening, understanding, acceptance, tolerance, confirmation and satisfaction. Individuals may attempt to express themselves and their experience using these terms to health professionals. Whilst the physical and cognitive aspects of the condition have received attention in the literature, there has been less attention devoted to the role of emotional factors, and to the education and behaviour programmes applied as intervention approaches for FMS. Therefore, this research study incorporates an assessment of this construct, in addition to patients' own perspectives and experiences.

The term alexithymia is derived from the Greek words "a" (lack), "lexis" (word), and "tymos" (emotion). It was first coined by (Sifneos, 1972), and recent studies have highlighted that it means difficulty in classifying and describing feelings. Alexithymia is a multifaceted identity characterised by in ability to control external feelings. Furthermore, a recent study has argued that alexithymia has multidimensional characteristics (Di Tella and Castelli, 2016).

Alexithymia is a major disturbance of cognitive function. It is a deficiency in the cognitive development and control of emotion. Therefore, emotional features associated with FM could reflect the appearance of alexithymia. (Baeza-Velasco et al., 2012). It has been demonstrated that FMS patients have a high rate of alexithymia, including anxiety and depression (De Gucht and Heiser, 2003). Furthermore, a number of studies have reported the existence of a relationship between alexithymia, anxiety and depression (Di Tella and Castelli, 2013). A recent study has shown that the prevalence of alexithymia-related behaviours in fibromyalgia sufferers was high, ranging between 15 to 20% of the population (Castelli et al., 2012). Furthermore, a number of studies have reported the existence of a relationship between alexithymia, anxiety and depression. (Di Tella and Castelli, 2013, Bagby et al., 1994).

1.4.28. Etiology of Alexithymia

Alexithymia is thought to be a personality trait. It appears to have an association with a few chronic conditions, including FMS, and its hypothesized that alexithymia is

correlated with brain abnormalities (Maes and Sabbe., 2014). It is unclear what causes alexithymia, although several theories have suggested that genetic, neurological, and environmental factors are involved, although the role of genetic and environmental factors is still unclear. A study by Muftuoglu et al. (2004) reported that alexithymia features in migraine patients. In addition, it was pointed out that migraine patients were significantly more alexithymic, depressive, and anxious than healthy people (Muftuoglu et al., 2004). Furthermore, it was found that psychological distress was strongly liked to pain, and emotional aspects were correlated with autonomic reactivity, such as that of the autonomic nervous system and the HPA-axis system, which explain a considerable part of the alteration of pain process in FMS patients (Muftuoglu et al., 2004). Moreover, neuroimaging research has indicated that alexithymia can be correlated with a higher-level of cognitive deficiency in assessing emotional inputs, and the absence of neuronal structures representing the lower level of processing of emotional stimuli (Berthoz et al., 2002).

FMS patients struggle to express themselves, which suggests that difficulties in the description of complaints could be due to alexithymia, characterized by the incapability to differentiate emotions from somatic states (Haviland et al., 2000). It has also been found that patients with alexithymia exhibit cognitive characteristics such as a dearth of fantasy, imagery, and daydreaming. Thus, because of the difficulty to experience and express emotions, alexithymia has been associated with somatosensory amplification, which is a tendency to focus on somatic sensations (Bradley, 2009a).

1.4.29. Treatment of Alexithymia

A recent Italian study investigated the link between alexithymia and depressive symptoms in fibromyalgia, in 181 subjects with FMS, and a healthy control group, using the Hospital Anxiety and Depression Scale and the Toronto Alexithymia Scale. It was concluded that a stronger link between alexithymia and depressive symptoms was found in FMS (Ghiggiaa et al., 2017). Furthermore, alexithymia can exacerbate depression and pain symptoms, but health professions treat alexithymia by concentrating on developing skills such as emotional self-awareness and vocabulary for emotions. (Bradley, 2009b, Bradley, 2009a)

The therapeutic strategy to deal with FM patients who have high alexithymia involves treatment modalities that offer the possibility to expand emotional consciousness, and the ability to direct and balance instinctual pressures and emotional arousal during cognitive procedure (Madenci et al., 2007). A higher comorbidity of psychiatric conditions underscores the importance of psychiatric interventions in FMS patients (Haviland et al., 2000), and as such, the study of alexithymia provides an interesting and important direction in fibromyalgia research. The extent and role of alexithymia in people with fibromyalgia are explored in this research study.

1.4.30. Conclusion

FMS is a complex syndrome that is often difficult to diagnose, and is extremely poorly understood. Furthermore, numerous aspects of this condition remain unidentified, and its pathogenesis is still not fully clear. However, modern functional neuroimaging techniques are providing important data about the involvement of the CNS. FMS should not be considered a diagnosis of exclusion, and the recently published ACR 2010 criteria attempt to elucidate specifications for the differential diagnosis of FMS. The evidence suggests that a multidisciplinary approach to treatment is optimal. The clinician must take into consideration both drugs, in particular antidepressants and other neuromodulators, as well as non-pharmacological treatments, such as CBT. Treatment approaches are rarely standardised, and there is great variability in management. Furthermore, patients' experiences of the condition need to be fully understood in order to manage the condition appropriately. Despite developments in research, FMS remains a challenging condition for many clinicians and patients, with many gaps in the existing literature.

1.4.31 Aims and Objectives

The overall purpose of the study is to capture service users' and service providers' views and experiences of fibromyalgia, and to explore health professionals' current practice in this light.

The thesis sought to answer the following research questions

1. What are views and experiences of service users regarding their condition the impact upon their lives and how these influence their

health care seeking behaviours and experiences of interventions?

2. What are the range of fibromyalgia interventions and the diagnostic/ assessment process they have experienced/sought?
3. What is current practice regarding fibromyalgia in the UK and what is current practice in Libya.

The aims of the study, corresponding to the two phases of the research, are as follows:

1. To explore FMS patients' views and experiences regarding issues that impact upon their condition.
2. To explore service users' and service providers' views regarding the experience and management of fibromyalgia.
3. To explore the extent to which emotional issues impact upon the experience of fibromyalgia.
4. To describe current FMS practice in the UK and Libya. This will provide information regarding the usual types of treatment and care for fibromyalgia, and the availability of services.
5. To consider similarities and differences in views and approaches to the assessment and management of fibromyalgia in the UK and Libya.
6. To explore service users' and service providers' views and opinions regarding the nature of fibromyalgia, and the interventional approaches used.

1.4.32. Aims of the First Phase: Interview Study

1. To explore the experiences of service users of the process of obtaining a diagnosis
2. To explore the emotional experiences of sufferers
3. To explore the experiences of the support received
4. To explore the experiences of coping with and managing daily living activities
5. To explore the interventions that have been accessed by sufferers, and their experiences of these interventions
6. To explore the experiences of living with pain

1.4.33 Aims of the Second Phase: Survey Study

1. To describe the current FMS practices of service providers in the UK and Libya.

2. To consider similarities and differences in views and approaches to the management of FMS in the UK and Libya.
3. To explore attitudes and opinions regarding the nature of fibromyalgia and the outcomes to the interventions used.

1.5. Thesis outline

The study is divided into six chapters. An overview of each chapter is given below.

Chapter One: Introduction and Review of Background Literature

The first chapter starts the thesis by introducing the study and presenting the research questions and the aims and objectives of the research. A literature review and theoretical analysis of the assessment and management of chronic widespread pain are presented in this chapter, including a brief review of intervention approaches. Moreover, an appraisal of the relevant contexts that support the objectives of this research is conducted. A critical discussion of the pathophysiology of the condition and its assessment and management is also provided.

Chapter 2: Overview of Research Methodology

This chapter describes the philosophical approach that informed the choice of research methodology adopted in this study, and the paradigms used to explore the experiences of people living with chronic widespread pain.

Chapter 3: Interviews with Patients

This chapter presents the in-depth views and the life experiences of FMS patients. A framework analysis was chosen to conceptualise the perceptions of participants, by illustrating the experiences and journeys involved in the diagnosis, coping with pain and its unpredictability, the availability of services, the interventions approaches used to treat fibromyalgia and their effectiveness, and emotional aspects that impact the daily living activities. The framework analysis focuses on the situations, activities and anxieties of participants regarding their condition, and highlights the overall theme identified. The chapter concludes with a discussion of the findings of the qualitative research on the experience of living with chronic pain.

Chapter 4: Survey of Health Practitioners

This chapter explores service providers' views and attitudes of assessments and intervention approaches used on FMS. Moreover, the chapter describes the current practice in the UK and the relevant consideration in Libya regarding FMS. The quantitative survey formed the method of data collection used, where the questionnaire was based on a previous study by Sim and Adams (2003b). The participants were recruited from the British Pain Society and the Libyan health and medical professionals (Physician, physiotherapists) and the results of the surveys were analysed to highlight the differences in the approaches used for the management of FMS between the UK and Libya.

Chapter 5: General Discussion, Conclusions.

The final chapter of this thesis describes the original contributions to knowledge made in this research. In addition, the chapter presents an analysis of the research findings regarding the diagnosis and the journey to diagnosis of fibromyalgia, the clinical features and the variability and unpredictability of symptoms; the experience of available interventions and the management of symptoms; and the emotional experience associated with the disorder. The lack of understanding of FMS and the role of self-management themes highlighted from the qualitative semi-structured interviews are also discussed in this chapter.

Chapter 6: Future Research and Recommendations

Finally, the thesis is concluded by highlighting the limitations of this research and providing recommendations for future research.

CHAPTER TWO: RESEARCH METHODOLOGY

2. Introduction

2.1. Aims of the Study

The overall aims of the study correspond to the study phases and are as follows:

1. To explore FMS patients' views and experiences regarding issues that impact upon their condition.
2. To explore service users' and service providers' views regarding the experience and management of fibromyalgia.
3. To explore the extent to which emotional issues impact upon the experience of fibromyalgia.
4. To describe current FMS practice in the UK and Libya. This will provide information regarding the usual types of treatment and care for fibromyalgia, and the availability of services.
5. To consider similarities and differences in views and approaches to the assessment and management of FMS in the UK and Libya.
6. To explore service users' and service providers' views and opinions regarding the nature of fibromyalgia, and the interventional approaches used.

The study detailed in this thesis aims to further develop the approaches already present in the growing body of research that questions diseases experience from the viewpoint of the person living with FMS. The significance of this study lies in the fact that very little research has been undertaken that specifically looks at illness experience in UK contexts. This chapter will describe the study's underlying philosophical hypotheses and methodological approaches. The chapter will conclude with a brief summary of ethics in such research. The studies are detailed in subsequent chapters**.**

2.2.Methodology

The methodology for this study has been carefully chosen by considering the phenomenon under investigation and the relevance to the research question. Research questions often help to dictate the methodological approach that can be used to manage and conduct a study (Creswell, 2009) A rationale for the use of a mixed methods for the two phases of the study will be discussed. The two phases will occur concurrently

with data collected and analysed separately (Creswell & Plano-Clark, 2011), with the findings considered together during interpretation in the discussion. The qualitative study in Phase 1will use semi-structured interviews to collect data and analyse data using the Framework approach(Creswell, 2013). Standardised questionnaires will be used to assess fibromyalgia impact and alexithymia. Quantitative survey data will be collected by means of an anonymous postal questionnaire in Phase 2. Most quantitative data will be gathered in the form of frequency counts and data will be analysed by means of appropriate descriptive statistics(Holloway and Wheeler., 2010) using SPSS software version 24.

2.3.Ethical Considerations

An ethics proposal was submitted to the Faculty of Health and Life Sciences, Northumbria University 3rd of March 2015, with ethical clearance for this study being granted the 12th of May 2015 (reference HLSSA300415, see the Appendix 3). Voluntary and informed consent was ensured. Each participant was provided with a participant information sheet, which advised on the purpose and nature of the study in this research. Participants had the opportunity to withdraw at any point. Moreover, care was taken to ensure that the wellbeing and safety of the participants. Participants well-being and dignity throughout exceeded the interest of the research process (Wassenaar & Mamotte, 2008). In addition, confidentiality was ensured to the all participants. No names were be used in this research in order to protect the identity of the participants.

2.4. Research Perspective and Philosophy

The inquiry paradigm is a set of the beliefs about the nature of reality and how it can be understood. These beliefs can be understood through the ontology and epistemology. The ontology is a concepts of knowledge about the type of fundamental entities that occur (Robson, 2011) .Epistemology is a philosophical assumption of how researchers gain knowledge and behind the theory is how things can be known and can be informed by qualitative literature (Carter and Little, 2007). The ontology looks at the assumptions about the nature of knowledge and reality, whereas the epistemology is concerned with understanding what kinds of knowledge can be studied (Healy and Perry., 2000). The researcher's philosophical position clarifies

his/her understandings about the nature of knowledge and reality (ontology) and his/her relationship with knowledge and reality under research (epistemology) (Blaikie, 2007) This research project will explore, the processes involved and the factors are influencing interventions for fibromyalgia treatment approaches.

2.5. Pragmatism

Pragmatism is associated with mixed methods research on the use of multiple methods of data collection to inform the phenomena under study. It is an overarching philosophy, in terms of specific philosophy assumptions (Creswell, 2018). Pragmatism differs from postpositivism and focuses on the outcomes of the research situations, and consequences of inquiry rather than antecedent conditions,(Creswell, 2013). There are also many interpretations of pragmatism that have arose in the social science, but for many pragmatism as a worldview arises out of actions, situations and consequences rather than an antecedent conditions, there is a concern with applications, what works and solutions to problems.

The problem is most important, and researchers decide the most appropriate approaches or methods to understand the problem (Creswell, 2011) . There are many mixed methods researchers and theorists that draw strong relations with mixed methodology and pragmatism , it is a practical approach to a problem and has strong relations with mixed methods research (Bazeley, 2003).

Pragmatism avoids ontology by arguing that the reality is known through the human experience of it, it offers an epistemological basis for what researchers do normally seek to find a solution for issues identified through their experience (Neale, 2009). Pragmatism legitimises the mixing of qualitative and quantitative methods so that they solve research problems better than one approach employed in isolation (Neale, 2009), in order to fully capture service user and service provider views and experiences of Fibromyalgia a mixed methods approach was required.

2.6. Mixed Methods Theory and Practice

Mixed methods research incorporates the mixing of qualitative and quantitative data in a particular study or set of related studies, which may give a better comprehension of research issues and complex phenomena than either approach alone (O'Cathain, 2009). Fibromyalgia is a complex phenomenon. Quantitative and qualitative health

research using mixed methods is increasing. However, health care research has been historically dominated by medical research with an agenda for treatment and cure using experimental clinical trials rather than the more subjective experiential agenda of qualitative inquiry (Creswell 2007).

In the current study a mixed methods design has been adopted underpinned by a Pragmatism philosophy. This design also fits within the Medical Research Council guidance for complex interventions (Craig et al., 2008) As it establishes the state of the evidence and stakeholders views and will also elucidate what is usual treatment for FMS in the UK as this has not yet been explained. The information gained from the studies will provide requisite information upon which to develop and interventional randomised controlled trial in the future.

The limitations of qualitative research alone include the complexity of analysing and doing justice to, the large quantities of data collected and issues related to rigour and quality, and transferability (Holloway and Wheeler., 2010). Many researchers are beginning to develop and employ mixed method designs in health and social sciences (Bergman, 2008). The mixed methods approach in this study involves two phases occurring in parallel. This will allow development of a comprehensive understanding the experience of Fibromyalgia and interventions from the patient perspective, and the wider context of treatments for Fibromyalgia from clinicians perspectives.(Creswell, 2007). The researcher bases the inquiry on the assumption that collecting diverse types of data best provides an understanding of a research problem. The study includes a broad survey in order to generalize results to a population and then focuses, with a qualitative phase including, open-ended interviews to collect detailed views from participants(Creswell, 2013).

It has been argued that there are many advantages of mixing both qualitative and quantitative research in single study and numerous mixed methods been reported in the scholarly journals for social scientists. Mixed methods allow the researcher to generalize the findings to both a population and develop a detailed view of the meaning of a phenomenon or perception for individuals. The advantages of collecting both closed ended quantitative data and open ended qualitative data prove advantageous to best understand a research problem (Creswell, 2013). There are four procedures or frameworks that include (convergent or parallel, explanatory,

exploratory, and embedded) to guide an examination of the use of mixed methods research for collecting both qualitative and quantitative data (Creswell, 2013). Within the current study a convergent or parallel approach was employed (Creswell, 2011), in order to capture the different types of data required separately, analyse these and then interpret the implications of the findings from each study within the discussion.

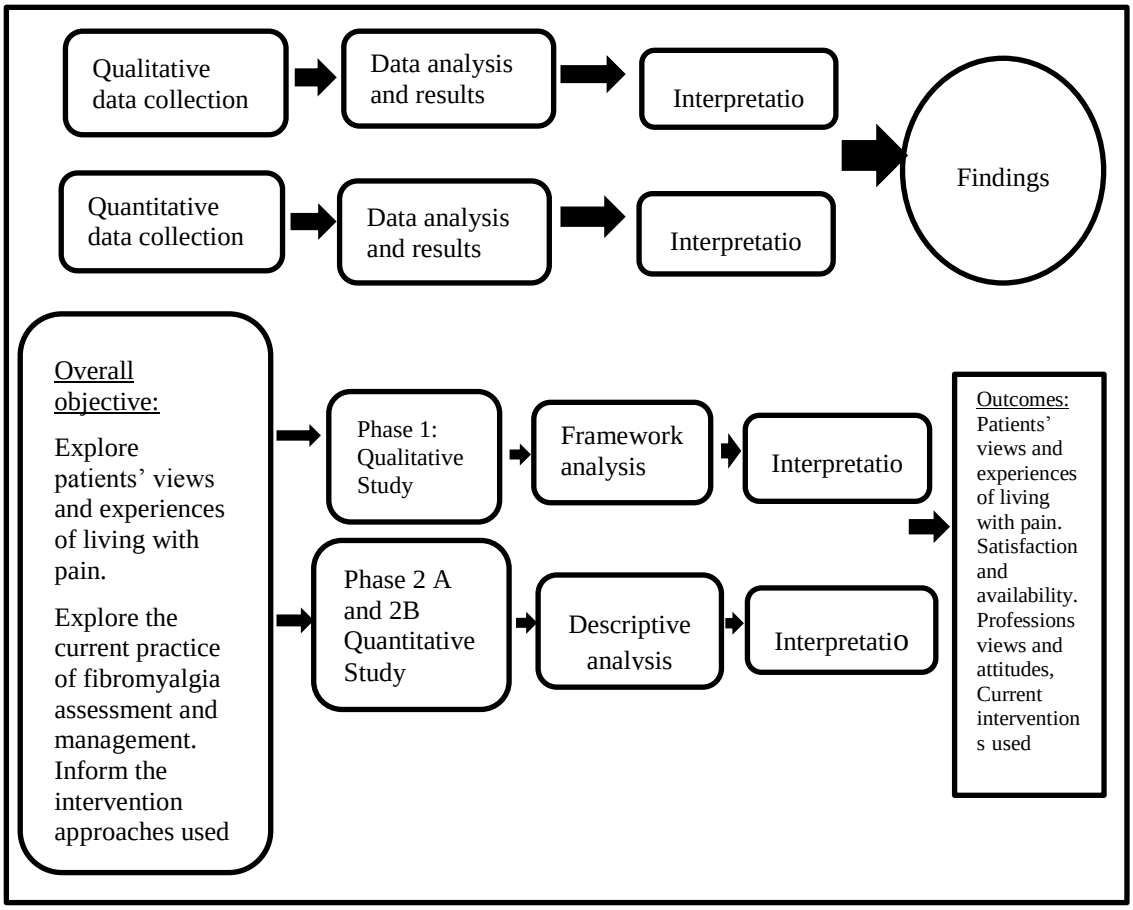

Figure 2.1 convergent parallel design of the thesis, informed by(Creswell, 2011)

Philosophical distinctions between quantitative and qualitative have become so blurred that researcher are left with an impression that differences among them are merely technical(Smith and Heshusius., 1986). In fact mixed method is not explored the same phenomena and been reflected that quantitative methods cannot access some of the phenomena that health researchers are focus on for instance, lived experiences as patients, social interactions and patients' perspective of health care professional prospective (HCPs) patients interaction. The information will, describe the new interactions and debate between service providers and service users points view of

assessing and managing FMS and living experiences of been diagnosed with FMS. A framework is aimed of supporting the integration of different elements of the research process to ensure the effective and successful study of social and educational phenomena. In the framework there is no content structure of represents process and activities it can be realized as module that describes the process of plane and carrying out the research (Plowright, 2011).

2.6.1. Qualitative Sampling

Interviews will involve people living with FM; recruited from a fibromyalgia self-help group in the North East. The sample is purposive including both men and women aged 27-60 years. Participants will be approached via email to be confirmed to date and time of the interview. Initial contact will be made via the Chair of the Fibromyalgia Group in the North East and the researchers invited to attend a general meeting to explain the study. Members will then be asked to provide their contact details if the wish to be contacted regarding participation in the study. Patients will not be recruited from the NHS.

2.6.2. The Qualitative Interviews with Stakeholders (Phase 1)

Interviews with individuals who have knowledge of the fibromyalgia condition can provide a valuable perspective. Interviews are the most commonly used data collection strategy in qualitative research (Nurkoosing, 2005). (Whittaker, 2012 , Lumley et al., 2002)., (Bowling, 2009) cites the following as ‘advantages’ of utilising face-to-face interview methods, interviewers can probe fully greater depth of information can be obtained, and more complicated and detailed questions can be asked to clarify any uncertainties. These interviews will aim to capture additional information so as to further elucidate the experiences and perspectives of individuals. Semi-structured interviews with the fibromyalgia self- help group will be conducted upon a purposive sample of approximately 12-15 participants, based upon previous qualitative studies such as Tamara Marıa et al. (2017) set in Spain involved 13 women with FMS and a previous UK study by Lempp et al. (2009) involved 12 patients, each providing in depth experiences. All the information collected will be kept confidential. With participants assigned a code and any other identifiable information in a secure filing cabinet at Northumbria University accessible to only the named researcher. This will

also be encrypted electronically. Only the research team will have access to this information. Any quotes that are used in the final report will be anonymised. Names and details of participants will not appear in any printed document. Case report forms (CRFs) – for example completed interview data will be stored securely in a locked cabinet at the Northumbria University and destroyed a year after the end of the research, data can be withdrawn of the request is made before a specified deadline.

In order to help describe the sample recruited in this qualitative phase, The Toronto Alexithymia Scale (TAS-20) will be used for the participants to measure different facets of alexithymia including difficulty in identifying one's feelings and in distinguishing between emotions and bodily sensations and pain sensitivity. Toronto Alexithymia Scale (TAS-20) has become a widely used instrument for assessing this psychological construct in both research and clinical practice.(Bagby et al., 2006, Parker et al., 2003). Research has demonstrated that targeting alexithymia in other conditions can lead to clinical benefits; a possible research question could be whether interventions that aimed to enhance emotional expression or processing could lead to improved mental or physical health in those with FMS. A greater attention to the role of alexithymia in FMS may provide elucidation of emotional processing in fibromyalgia with its consequent effects on pain experience, affect and communication. (Graugaard et al., 2004, Beresnevaite, 2000). The uses of self-report TAS in this research for assessing the impact of alexithymia on FMS patients by exploring how it is linked to FMS and the influences of alexithymia on patients' daily living.

In addition the Fibromyalgia Impact Questionnaire; (FIQ), and Toronto Alexithymia scale TAS-20) will be used in addition to the interview, this will extend the timescale of the interview by another 5 minutes. FIQ assesses impact of fibromyalgia subjective patient reports on scale, functional status instruments and clinical observations. The standardised scoring system provides an indication of the extent of impact of the condition upon the patient. Impact Measurement Scale (AIMS) was used to assess the content validity of 10 items, which consisted of work difficulty, feeling good, pain fatigue, rest and stiffness. (Bennett et al., 2009, Burckhardt et al., 1991). Therefore, to assess patients function and impact of fibromyalgia to augment the qualitative data, the validity of Fibromyalgia Impact Questionnaire measuring patient's' subjective

responses is a validated outcome measure frequently used in research studies of fibromyalgia. The TAS-20 used to indicate the agree or disagree with each statements on Likert scale, the results provided a TAS total score, and the three subscale score that measure different aspects of alexithymia include difficult identifying feeling(DIF),difficult describe feeling(DDF) and externally-oriented thinking (EOT. DIF measures the ability to distinguish specific emotions or between emotions and the body sensations of emotional stimulation, DDF, which assesses the ability to verbalise one's emotions to other people and EOT which evaluate the tendency of individuals to focus their attentions externally not on emotional experiences.(Lumley et al., 2007).

2.6.3 Analysis of Qualitative Data (Framework Analysis).

The qualitative phase of this mixed methods study will be analysed using the Framework Approach. The framework method sits within a broad family of analysis methods often termed thematic analysis (Gale et al., 2013). In the late 1980s Framework analysis was used in large scale policy research (Ritchie, 2003b) however has since been increasingly used in health research (Gale et al. 2013). These approaches identify commonalities and differences in qualitative data, before focusing on relationships between different parts of the data, thereby seeking to draw descriptive and/or explanatory conclusions clustered around themes (Ritchie, 2003). The Framework analysis provides clear steps to follow and produces outputs of summarised data to facilitate interpretation. These steps include familiarisation with the data, initial coding, followed by development of a thematic framework, application of this thematic framework to the remaining transcripts, and the thematic framework is developed as required based on emerging themes (Gale et al., 2013). Charts are then developed to provide a summary overview of the data grouped into themes, and this facilitates overall interpretation. During the charting stage elements and dimensions are explored within the data. Elements are small statements, which capture responses from individuals and are grouped into dimensions related to similar response. (Ritchie, 2003a). Following this dimensions are grouped into related categories, which following interpretation are refined and developed into overall final themes (Ritchie, 2003b). The Framework analysis is a flexible approach that can be adapted for use with many qualitative approaches that aim to generate themes, however, is not aligned with a particular epistemological, philosophical, or theoretical

approach(Gale et al., 2013), which fits with the approach of this thesis.

2.7. Medical Research Council Framework

A Framework for the Development and Evaluation of RCTs for complex interventions to improve Health has been published via the Medical Research Council MRC (De Silva. et al., 2014). Complex interventions are widely used in the health service, in public health practice, and in areas of social policy such as education, transport, and housing that have important health consequences (Pinnock et al., 2007). Complex interventions are usually described as interventions that contain several interacting components. There are, however, several dimensions of complexity: it may be to do with the range of possible outcomes, or their variability in the target population, rather than with the number of elements in the intervention package itself. Implementation research seeks to identify which techniques are effective for encouraging the version of evidence into practice and to provide information about 'real world' variability in effectiveness and cost effectiveness of interventions, and about the practicalities of introducing and sustaining new treatments or services (Pinnock et al., 2007, Pinnock et al., 2003). Consequently, evaluations of complex interventions should be informed whether or not the intervention was 'successful'and in a way that enables the intervention to be duplicated or modified for the purposes of further research or for larger scale implementation. It is important to provide a full explanation of the intervention application and implementation, and often beneficial to interpret the process of developing and implementing the interventions, as well as the results of the evaluation (Wight and Abraham., 2000 , Wight et al., 1998). The proposed two phase research described above will seek to explore important aspects associated with the condition. Within this research, an exploration of existent literature will be conducted and appraised. Following this a qualitative study with people living with FMS will be conducted to develop an in depth understanding of management of the condition and guide future intervention development. A descriptive survey (questionnaire) in the health and social research is to convey the validity of level of health care with a particular intervention and the various services it provides in the UK.

2.8. The Survey (Phase 2)

In order to elucidate current fibromyalgia practice, a survey method was used. Surveys allow the development of theory directly based on data collected by the researcher (Holloway and Wheeler., 2010, Creswell, 2007). Survey research grew with a positivist approach to social science, it allows researcher to gather information and test multiple hypothesis in a single survey. For this purpose a survey is appropriate when the researcher wants to explore behaviour and beliefs.

A survey technique is often adopted where there is not much knowledge and research exists, concerning the phenomenon being studied. An initial literature review reveals very little research on the subject of the standard care for fibromyalgia both in the UK and in Libya. This study aimed to develop upon previous research (Sim and Adams 2003), by surveying a large national population of arrange of health professionals in the UK. The survey's capacity for generating computable data on large numbers of individuals who are known to be representative of wider by practitioners as mean of capturing various of the elements of research phenomena (Bryman, 1988).

Therefore, participants were recruited from the British Pain Society for survey phase 2A and for survey phase 2B were recruited from Libyan healthcare professions, the questionnaire was adopted version from previous study by (Sim and Adams, 2003a), using a mailed questionnaire. The questionnaire modified a previous version used in the study above. The study was further extended to conduct an exploratory study in Libya with Libyan health and medical professionals regarding chronic widespread pain practice, management and assessment in Libya.

In this research, quantitative and qualitative research will be regarded as two emphatically different elements to explore the dimensions of the research study questions. This research project will explore, the processes involved and the factors are influencing interventions for fibromyalgia treatment approaches.

CHAPTER THREE

A Qualitative Study of the Experiences of People Living With Fibromyalgia (Chronic Widespread Pain), Regarding Assessment, Management and Interventional Approaches

3. INTRODUCTION

3.1 Background

Fibromyalgia is a chronic musculoskeletal pain condition that is characterised by being challenging for healthcare professionals, due to the uncertainty of diagnosis, processes and treatment. The condition is often considered invisible, raising questions of credibility and understanding, and the impact of symptoms on physical and emotional aspects (Friedberg, 2010a). Diagnostic labels thus become an important factor in the experiences of individuals living with the condition finding the location and intensity of pain to be unpredictable and affecting the level of activities (Friedberg, 2010b). The literature has either direct or indirect implications for primary care and professional practice, in relation to such issues as developing a more sensitive understanding of patients' symptoms, and a more collaborative and fruitful therapeutic relationships. In contrast, the use of social, family and support group networks were found to be more psychological, and based on self-identity or self-image in a population of individuals living with chronic illness (Dwarswaard et al., 2015).

Although a number of studies have been conducted to investigate the experiences of people living with fibromyalgia, many of these are not UK based, and there is considerable heterogeneity in the foci of studies, as identified in a previous qualitative synthesis study (Sim and Madden., 2008). Twenty-two separate studies were identified in Sim & Madden (2008) qualitative synthesis, and each study was evaluated using methodological criteria to provide a context for interpretation of substantive findings. The meta-synthesis review identified four central themes: experience of symptoms, search for a diagnosis, legitimacy, and coping. The intangible, ambiguous and invisible nature of pain in FMS is problematic for both patients and healthcare professionals, and raises important issues of legitimacy. As in other 'invisible' conditions, the individual's social and moral credibility are under potential threat. The diagnostic journey undertaken by people with FMS, and the meaning attached to the diagnostic label, are important issues in the individual's experience of the condition.

Most of the studies of patients' life experiences have tended to focus on the experiences of diagnosis and healthcare, and how the condition affects daily activities, including social interactions and personal relationships with GPs and HCRs regarding

the availability of intervention approaches, and how they currently treat patients. 'However this identifies an unmet need to focus on patient views of living with pain and the emotional factors that impact their condition'.

A recent study in the UK by Sahar et al. (2016) included participants diagnosed with fibromyalgia (n=148), in a cross-sectional online questionnaire focused on self-efficacy, acceptance, and coping. Participants with fibromyalgia were recruited from fibromyalgia support groups and organisations across the UK, and the United States of America (UAS) used online settings. Measurement outcomes were used, which included the Arthritis Self-Efficacy Scale, Chronic Pain Acceptance Questionnaire (CPAQ), Revised Fibromyalgia Impact Questionnaire (R-FIQ), Medical Coping Modes Questionnaire (MCMQ), The Present Pain Intensity (PPI), Tampa Scale for Kinesiophobia, and Pain Catastrophising Scale (PCS). Data was analysed using IBM SPSS 19. The study found no significant relationship between symptoms intensity and fibromyalgia impact.

Coping and self-management is frequently observed as having multiple elements, in which self-efficacy is a central factor (Carnes et al., 2012, Miles et al., 2011). Thus, providing patients with knowledge may develop confidence with psychosocial aspects, and support people with chronic musculoskeletal pain such as FMS and fatigue syndrome to self-manage. Due to this study being a questionnaire, there is scope to develop qualitative literature exploring these areas to enhance depth of understanding.

A literature review was conducted to identify qualitative literature exploring individuals living with chronic widespread pain and fibromyalgia. Aveyard (2019) discusses a narrative or literature review can follow some systematic approaches such as transparent search terms and clear criteria. This approach has been adopted for this section.

. The search terms and databases searched are shown in Table3.1

Table 3. 1: Show the search teams to identify existing literature review.

Database	Search terms
Science Direct	Fibromyalgia and experience and qualitative Fibromyalgia and interventions and qualitative Fibromyalgia and Alexithymia and qualitative Interventions and chronic pain Pain experience and fibromyalgia Fibromyalgia and Patient perception Fibromyalgia and Patient satisfaction Fibromyalgia and health care Fibromyalgia and patient relationship Fibromyalgia and quality of life Fibromyalgia, Qualitative, interview, subjective and experience Fibromyalgia and Homeopathy
PubMed	PubMed and Medline searches were performed using the keywords Fibromyalgia and experience and qualitative Fibromyalgia and interventions and qualitative Fibromyalgia and Alexithymia and qualitative

Existing qualitative literature that has explored experiences of daily living with fibromyalgia from patients' perspective were identified from 17 qualitative studies. The studies were found from searches of the PubMed and Science Direct databases. Table 4.2 details the qualitative studies identified with this search, and their key characteristics and findings.

Studies included in this study were qualitative and focused on individuals' experiences of living with a chronic widespread pain (fibromyalgia). Publications were all written in the English language from the UK, USA, the Netherlands, South Africa, Turkey, Sweden, Spain, New Zealand, Finland and Norway. The narrative review included literature published after 2009 to explore the literature published following Sim and Madden (2008).

Table 3.2. Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
English language only Published literature only 2009 towards Studies that explored patients perceptions of living experiences with pain	Not English language unpublished literature pre2009 Studies that explored patients perceptions quantitatively included systematic review
Studies that explored the experiences effectiveness of interventions approaches	A descriptive quantitative studies
studies are related to chronic widespread pain	Qualitative systematic reviews

1 Table 3.3: Characteristics of qualitative studies located during the literature search

Author	Design	Number of participants	Findings
Tamara Marıa et al. (2017)	An interpretive qualitative study	13 women	The physical symptomology, guilt, fear and a lack of understanding compromise the coping process. Women need the support of their partner, their socio-family environment and health professionals. Nurses can aid the successful adjustment to complications related to fibromyalgia.
Armentor (2017)	Qualitative descriptive	20 women	Skepticism, disbelief and a lack of comprehension often led participants to avoid social interactions in attempt to hide from the stigma associated with disputed, hidden illness.
Vincent et al. (2016)	A descriptive qualitative study	44 participants	Avoiding physical activities may indicate a lack of knowledge of or ability to use healthy coping strategies, and therefore, future research could evaluate the potential effects of teaching patients healthy coping strategies as one method to deal with symptom flares.
(Cooper and Gilbert, 2016)	A qualitative study utilising in -depth interviews	15 people	Support from family, partners, and peers plays an integral role in the process of accepting fibromyalgia diagnosis and seeking help from healthcare providers.
Juuso et al. (2016)	A qualitative approach utilising in -depth interviews	15 women	Women with FM experienced incapacity to work as they had previously and eventually accepted that their work life had changed or reached its end. Since their work had great significance in their lives, feelings of loss and sorrow were common. Women who were working, unemployed, or on sick leave described feelings of fear for their future work situations.
Eilertsen et al. (2015)	Qualitative thematic interviews	95 patients	The finding of this study similarities and differences experiences of fatigue were found across a long-term illnesses. Unpredictable fatigue, sleepiness were commonly expressed with pain and increased stress sensitivity. There were also a lack of energy as was the impact on social relationships and regarding how the patients managed their daily life .All patients felt a lack of understanding and disbelief from others.

Calsius, et al 2015	A phenomenological-hermeneutic approach	30 patients	The study found that As alexithymia had no influence on the description of body awareness BA, it seems that FM patients primarily fail to express their BA without in fact being disembodied.
Toussaint et al. (2014)	Qualitative study utilising -focus Groups	13 women	Forgiveness education is acceptable and feasible in patients with fibromyalgia. This justifies further exploration of forgiveness as an emotion-focused self-management strategy to decrease psychological distress.
Dennis et al. (2013)	Qualitative thematic interviews	20 patients	Participants described enduring the course of a 'giant mess' of unpleasant symptoms, some of which were understood to be symptoms of fibromyalgia and some the interactive or parallel effects of comorbid illness. The respondents also demonstrated their considerable efforts at imposing order and sense on complexity and multiplicity, in terms of the instability of their symptoms. They expressed ambivalence towards diagnosis, doctors and medication, and we noted that each of the above areas appeared to come together to create a context of relational uncertainty, which undermined the security of connections to family, friends, colleagues and the workplace.
Matthias et al. (2012)	Qualitative interviews	26 patients	patients identified the nurse care is playing an important role to help patients find what works for their pain; holding patients accountable for their pain management, also, motivating and providing emotional support to patients.
De Vries et al. (2011)	Qualitative study semi-structured interviews	21 subjects	The study found that behaviours promoting staying at work such as: raising adjustment latitude, changing pain-coping strategies, organizing modifications and conditions at work, finding access to healthcare services, and asking for support. Motivators and success factors for staying at work may be used for interventions in rehabilitation and occupational medicine, to prevent absenteeism, or to promote a sustainable return to work.
Rodham et al. (2010)	Qualitative semi-structured interviews	Four women with FMS	Loss of identity' played a significant role in the way in which carers and people with FMS alike experienced and managed FM. This was compounded by the lack of belief, understanding and negative attitudes expressed by amateur people and professionals.

Escudero-Carretero et al. (2010)	Qualitative study interviews focus groups.	20 women and 1 man	Patients describe a difficult experience, with symptoms that may involve incapacity for daily activities. Until knowing their diagnosis, they feel a lack of understanding and loneliness. They develop different coping strategies, as looking for information or association. From the health system they expect: attention and a fast diagnosis, accessibility to consultations, medical exams and therapies or an impulse for research. They want trained professionals, proactive attitudes, interest, empathy and information.
Sallinen et al. (2011)	A qualitative study, narrative interview	20 women	Four types of experience concerning work ability were identified in the narratives: confusion, coping with fluctuating symptoms, being 'in between' and being over the edge of exhaustion. Severe pain and fatigue symptoms, combined with a demanding life situation and ageing, seemed to lead to substantial decrease in work ability and functioning over the long term.
Lempp et al. (2009)	A qualitative study - interviews	12 patients	Patients expected more consultation time and effective treatment than they received. Subjective experiences and objective physical and emotional changes were non-overlapping.
Arnold et al. (2008)	qualitative study ,focus group	48 women	Fibromyalgia had a considerable negative impact on social and occupational function. Patients reported disrupted relationships with family and friends, social isolation, reduced activities of daily living and leisure activities, avoidance of physical activity, and loss of career or inability to advance in careers or education.

2

3.2.1 Experiences of living with Fibromyalgia

Table 3.3 provides an overview of the current literature focusing on living with Fibromyalgia. This literature will be discussed in further detail to highlight what is known within this area, and the need for future research. In a qualitative study conducted in a rheumatology outpatient clinic, 12 patients were interviewed at medical school which included 11 female and 1 male age range of patients were 20-69 years (Lemp et al. 2009). The qualitative interviews were conducted in the UK, and aimed to understand the patients' experience of living with this long-term condition (Lempp et al., 2009). Content and discourse analyses were used to analyse the data. The interview guide consisted of four areas, namely the experience of the onset of the illness, the development of FMS following diagnosis, the impact on patients' lives, work and family, and the patients' expectations and experiences when seeking medical help in primary and secondary care. The study found that patients expected more consultation time and effective treatment than they felt they received. Subjective experiences and objective physical and emotional changes were non-overlapping. This study however, did not explain the associations between these issues, and the explanatory models of patients and staff need to be considered.

The four areas were explored by Lempp et al., (2009), where the themes presented included life changes before and after diagnosis, health identity change, and quality of care. The lack of knowledge about FMS by patients, healthcare providers and the public , Patients expected more consultation time and effective treatment than they received. This study on the experience of living with pain is similar to semi-structured interviews that gather in-depth views on the experiences of living with FMS.

In a recent qualitative study by Cooper and Gilbert (2017) based in South Africa, historical data was collated from n= 15 participants, focusing on the diagnosis of fibromyalgia, the participants were all women aged between 23 and 59 and diagnosis occurred in private healthcare settings . The study conducted in-depth interviews, and narrative analysis was used for data analysis, which is a comparable procedure to those found in other social support literature in the Netherlands and the UK (Dwarswaard et al., 2015, Campbell et al., 2011). The social factors on employment was related to fibromyalgia and musculoskeletal chronic pain conditions, with little attention to the

influence of informal social support. The findings described fibromyalgia as a chronic illness that is hidden, and is based on a diagnosis of exclusion, which can result in challenges to credibility. Furthermore, the study observed that individuals experience widespread chronic pain that appears to affect their daily living activities. The study limitations included the context of the study, as healthcare in South Africa may be different to the UK, thus limiting transferability to this the UK context.

Many studies have focused on the experience of diagnosis (Armentor, 2017, Matarın Jimenez. et al., 2017, Embuldeniya et al., 2013) with these studies, focusing on other aspects of patients' experiences, such as social support and effectiveness of medications, rather than understanding pain. Alongside this explorination of what works best for FMS patients in relation to pain (Vincent et al., 2016, Eilertsen et al., 2015) has been explored. Other complex aspects of the condition include living with a chronic condition related to functional disability that affects social and familial relationships. As such, individuals living with chronic widespread musculoskeletal pain experience discuss diminished social, recreational, and community activities, and thus a decrease in the ability to maintain social relationships. Due to the importance of these aspects, further research is required in this area (Sim & Madden 2008).

In a qualitative study conducted by Escudero-Carretero,et al(2010) the experiences of patients with FMS towards the health system and its professionals were explored. Patients with fibromyalgia were included (n=20) including one male. A content analysis was used in the study for delving into patient experience. The participants were recruited through health professionals in the Andalusian Health Service and patients' associations. The finding of the study were included that, patients describe a difficult experience, with symptoms that may involve incapacity for daily activities. Until knowing their diagnosis, they feel a lack of understanding and also loneliness. They develop different coping strategies, as looking for information or association. The study presents a limitation of not being conducted in the UK, therefore limiting transferability to a UK health context.

The invisibility of the illness creates difficulties for individuals who are affected in terms of work and social activities. A study by Armentor (2017) used a convenience sampling process in a qualitative investigation about women living with FMS. The study was based in a rheumatology clinic, and a snowball sample consisting of 20

women participated in this study, all 20 women were diagnosed 12 years before the study. Participants were recruited from local rheumatologists' offices and snowball sampling from the referrals of existing interviewees, and the various approaches used by people with FMS to manage their social roles with others, including family, friends and medical professionals, were explored. The findings suggested that disbelief and a lack of understanding often led participants to avoid social interactions with friends and family, in an attempt to hide from the stigma associated with an invisible and contested illness. Participants reported that the lack of awareness and knowledge about FMS contributed to creating a sense from others that the illness is not real. Awareness and knowledge of FMS did not always relieve stigma. As this study was conducted in the USA, the results may not suitable for trasnferability to the UK population, due to the different healthcare systems and availability of interventions between the two countries. Research is therefore required to capture rich data from a UK based sample of people living with fibromyalgia.

A recent qualitative study by Vincent et al. (2016) explored the characteristics, causes, and management strategies of fibromyalgia flares. A total of 44 participants (30 women and 14 men), recruited from an existing, national registry of patients with fibromyalgia who have been seen at Mayo Clinic in Rochester, USA. Using seven open-ended questions, patients were asked to describe how a flare differs from their typical fibromyalgia symptoms, and how they coped with fibromyalgia flares and the factors associated with flares. Content analysis was used to analyse the results. The authors sought to understand how patients perceived fibromyalgia flares, and what triggers and alleviating factors patients identified for their symptoms. The study found that flares were associated with the avoidance of physical, social, and psychological stimulation. Avoiding activities may indicate a lack of knowledge of or ability to use healthy coping strategies, as for some participants, social interactions were emotionally and physically challenging. There were some inherent limitations in the study, which included the fact that data was collected by text response to the survey, rather than using interviews or focus groups to allow for deeper understanding of the experience. Thus, to avoid such a limitation in this research, qualitative semi-structured interviews can be used in order to gather in-depth information regarding patients' experiences of their condition. Another limitation of the US-based study was that authors did not specifically conceptualise the flare ups and their fluctuating

symptoms regarding pain or fatigue level of severity, which are key symptoms of fibromyalgia. Similarly to a number of other studies described, this study was conducted in the USA, and as such, it is important to explore a UK based population given the differences in healthcare between the two countries.

In a qualitative study conducted by Eilertsen et al. (2015) to investigate the fatigue experience of illness, and its impact on daily living across several long term illnesses including fibromyalgia, multiple sclerosis, ankylosing spondylosis, and stroke, interviews were conducted with 95 mixed Northern European participants, comprising 66 women and 29 men. Of which 25 were FMS patients, the interviews were carried out at places chosen by the patients. Similar experiences of fatigue were found across different long-term illnesses in this study. Unpredictable fatigue and sleepiness were commonly expressed with pain and increased stress sensitivity. There was also a lack of energy, which had an impact on social relationships and on how the patients managed their daily activities. All patients felt lack of understanding and disbelief from others. The large variation in how long the participants had suffered from their illnesses may be a limitation of this study. Thus, some differences identified in the analysis might reflect differences in how the interviews were conducted, rather than actual differences between diagnostic groups. The study highlighted the similarity of the experience of pain and fatigue across a number of long-term conditions, and that such symptoms are not specific to fibromyalgia.

3.2.2. Emotional Aspects of Fibromyalgia

Emotional aspects of fibromyalgia are considered an important part of the condition by many authors, yet, as identified from the literature review, there are few empirical studies that have specifically investigated the extent and nature to which the emotional component contributes to the experience of fibromyalgia. The concept of alexithymia was introduced in previous chapters, and some studies have indicated the difficulty that people with fibromyalgia have in emotional recognition.

A previous qualitative study by Calsius, et al (2015), of 30 women diagnosed with FM, patients were recruited from “Ziekenhuis Oost-Limburg” (ZOL) in Belgium (Genk) and in 10 different physical therapist practices data were collected. The study has supported the concept of lack of emotional recognition. Patients had been identified as having alexithymia and patients failed to express body awareness(BA) a

representation of alexithymia. The psychological factors contrasted with somatic dichotomy, the moral credibility of patients, and the experience of treatment used. Despite these limitations, this forms an interesting avenue for research. Therefore, identifying the emotional features of people living a chronic widespread pain conditions may affect their daily living activities and warrants further exploration. In this research, an assessment of emotional recognition using a standardised inventory was carried out to assess alexithymia and emotional recognition.

Emotional recognition may affect patients' perceptions of interventions in which they participate. A qualitative study by Matthias et al. (2012) of 26 female patients ages ranged from 24 to 62 were recruited from primary care clinics, the study aimed to ascertain the perceptions of a multicomponent intervention, tested in a randomised controlled trial for people with chronic musculoskeletal pain. Patients in this study were interviewed at the Veterans Affairs AV medical centre, at which they enrolled in Evaluation of Stepped Care for Chronic Pain (ESCAPE). As grounded theory guided the qualitative analysis, the findings of this study identified that self-management education was particularly significant. Patients identified the nurse care manager who administered the intervention as being integral to their ability to self-manage their chronic pain. Furthermore, the study depicted self-management as involving more than activities and strategies, but also acknowledged the central role of relationships and support in pain self-management. Patients in this study were all veterans of the recent wars in Iraq and Afghanistan, sampled from one VA primary medical centre. Given the sometimes unique experiences of veterans, all results may not apply to patients with chronic pain cared for in other clinical settings. Participants were interviewed only one time, a median of two months after completion of the intervention. The investigators were unable to ascertain how long the effects of the support from the nurse lasted after patients completed the study and were left to self-manage on their own. The study not only acknowledged the role of self-management education as part of a multicomponent intervention, but also identified components involved in facilitating self-management. Experiences of self-management were therefore explored in this research, and are discussed in the subsections to follow.

A qualitative study by Sallinen et al. (2010) used a narrative interview method to collect the narrative life stories of 20 women with fibromyalgia. Participants were recruited from rehabilitation courses in the Rheumatism Foundation Hospital in

Heinola, Finland. Data was analysed by using stepwise regression to elicit the impact of peer support, as described and reflected on in the patients' narratives after rehabilitation intervention. The study identified four main domains of experiences of peer support, namely permission to talk, need to information, reciprocity, and self-evaluation through comparison. The meanings ascribed to peer support were mainly positive, although the participants also expressed thoughts about fear of future, hopelessness and mental health issues. A major limitation of the study is small number of participates who were volunteered in the rehabilitation groups. The importance of the support domains was further explored in the current study, in addition to exploring other avenues of how people with fibromyalgia access support and information. Such knowledge should allow the development of better healthcare services, contribute towards a more holistic management of FMS, and provide support to those who had recently been diagnosed.

The literature on the experiences of living with fibromyalgia is diverse, particularly in terms of assessing and managing FMS, where various intervention approaches and the healthcare processes have been mentioned by individuals living with fibromyalgia. Furthermore, the literature has addressed a number of aspects that appear to influence singly and in combination, the experience of living with a long-term condition, such as fibromyalgia. There has been considerable focus on the impact of receiving a diagnosis, and on the varying experiences of the journey leading to diagnosis. Various other aspects that impact the experience of fibromyalgia have also been explored, including the experience of the symptoms of pain and fatigue, and the consequent impact on functional and daily activities, and the strategies to cope with the pain, fatigue and cognitive dysfunction. The impact on social and familial relationships has also been explored. A recurring theme explored by multiple studies is the impact of living with a condition, that despite considerable effects on daily living, has an element of 'invisibility', and a perceived lack of understanding by friends, family and healthcare professionals alike. Although psychosocial factors are often attributed to such conditions, the way in which emotional aspects influence cognition and other perceptions has not been widely explored. Furthermore, a large number of studies were not conducted in the UK. A qualitative study was therefore designed to explore these aspects, with the overall purpose of developing a framework model for the experiences of UK patients living with this long-term condition, in terms of symptoms description,

diagnostic processes, impact on daily activities, and management strategies.

3. 3 Aims:

Therefore in this chapter the following objectives have been identified.

This study addressed six key questions: -

1. To explore the experience of service users' in the process of obtaining a diagnosis

2. To explore the emotional experiences of sufferers

3. To explore the experiences of the support received

4. To explore the experiences of coping and managing daily living activities

5. To explore the interventions that have been accessed by sufferers and their experiences of these interventions

6. To explore the experiences of living with pain

3.4 Methods

A qualitative study design using semi-structured interviews was adopted, and the framework method of analysis was used to describe the individuals' experiences of living with the condition.

3.4.1 Design and sampling

As mentioned above, a qualitative design utilising semi-structured interviews was adopted. Participants were individuals living with FMS who had attended a Fibromyalgia Support Group in the North of England. Twelve individuals who had attended the support group consented to take part in the study upon invitation. A participant information sheet (which can be found in Appendix (7)) was sent to each participant in January 2016. The sample was purposeful, as it aimed to achieve a range of views and experiences of living with pain. The Fibromyalgia Support Group was appropriate to target due to the diversity of views, and the experiences of seeking assistance from different health service locations. To be included in the study, the participants had to be living with FMS, and have experience of living with FMS in the last three months. The interviews were recorded and transcribed, and the data was kept in a secure cabinet at the Northumbria University for the purposes of this study. The

interviews were listened to by the researcher only. The names of all individuals were changed to protect their anonymity, and all information collected was kept confidential, as only the research team had access to it. In addition, all quotes that were used in the final report were anonymised, and the names and details of participants did not and will not appear in any printed document. Case report forms (CRFs) (i.e. complete interview data) were stored securely in a locked cabinet at the Northumbria University, and will be destroyed a year after the end of the research. Data can be withdrawn if a request is made before a specified deadline.

Table 3. 4: Interview timetable.

Date	Interview 1	Time	Interview 2	Time
9th March 2016	P1	10 am -11:30 am	P2	12pm-01:30pm
14th March 2016	P3	10 am -11:30 am	P4	12pm-01:30pm
15th March 2016	P5	10 am -11:30 am	P6	12pm-01:30pm
16th March 2016	P7	10 am -11:30 am	P8	12pm-01:30pm
18th March 2016	P9	10 am -11:30 am	P10	12pm-01:30pm
23rd March 2016	P11	10 am -11:30 am	P12	12pm-01:30pm

3.3.1.1. Demographic Information

The 12 participants were all women with age of 27–60. see section 3.6.2 a rational for samble size .The current study included the onset of illness to FMS diagnosis was five years (range: 0.3–10). Nine participants had co-morbidities (chronic neck pain, chronic back pain, fatigue, depression, sleep disturbance, muscle and joint pain). Six people were retired, and four were unemployed. One participant was a paid worker and one participant was unemployed and disabled because of illness, the characteristics of the people involved are detailed in Table 3.5.

Table 3. 5: Characteristics of Participants.

Participants	Age	Sex	Employment	Point of pain experience (years)	Previous diagnosis
P01	60	Female	Retired	Three years	Polymyalgia
P02	38	Female	Employment states	Five years	Juvenile arthritis
P03	27	Female	Employed	One year	Guillain-Barre syndrome
P04	55	Female	Retired	Two year	Psoriasis(growing pain)
P05	54	Female	Retired	Five years	Diabetes

P06	45	Female	Unemployed	Twenty-five years	Knee arthritis
P07	46	Female	Unemployed	Ten years	Hypermobility syndrome
P08	62	Female	Retired	One year and two month	Plantar fasciitis
P09	60	Female	Retired	Ten years	Repetitive strain
P10	39	Female	Unemployed	Four years	Arthritis/ back pain
P11	39	Female	Unemployed	Five years	Hypermobility syndrome
P12	57	female	Retired	Ten years	Hypothyroidism

3.4.2. Data collection

The interviews were carried out with each of the twelve participants, and lasted an average duration of 1 hour and 30 minutes. Interviews were conducted from the 9th March to the 23rd of March 2016, at a time chosen by the interviewees. Participants provided written informed consent before the interviews started (the consent form used for this study can be found in Appendix (6)). The interview schedule guide, which was developed based on the literature review (Table3.6), was piloted with supervisors, and revised before commencing the actual study. The interview guide mentioned above was informed by previous qualitative studies that highlighted the limited literature regarding the understanding of individuals' views on pain experience and its asscoiatd emotional impact. The principal researcher moderated the flow of interviews through a schedule guide, which were digitally recorded and transcribed. The participants were aware that the researcher had a background in chronic pain management and was a physiotherapist, which allowed natural conversations to occur.

3.4.3. Schedule of semi-structured interview

As stated in Chapter 3, the preferred method of data collection in this research was semi-structured interviews, with the use of open-ended questions designed to motivate individuals to talk about their experiences of living with chronic pain. Patients' perspectives were taken into consideration when designing the interview schedule for this study. However, the interview schedule was flexible and used prompts where required. In all cases, the interview began with issues relating to certain symptoms such as pain and fatigue. Table 3.6 presents the interview guide used.

Table 3. 6: Interview Guide.

Opening questions

Questions were firmly inclusive to explore the service users' experience of living with chronic widespread pain (Fitzcharles et al.)assessment and management was started without specific influence.

History/ Background /symptoms

- What do you feel is going on in your body? Describe the feelings that you experience?
- What does the Fibromyalgia mean to you? Tell me about the History symptoms that you feel?
- What does the diagnosis mean to you, tell me how you feel when you were diagnosed with fibromyalgia?

Current state

- What impact has fibromyalgia had on their quality of life? "How has fibromyalgia affected your life?

Treatment

- What treatments do you have used to manage your condition?

Experience

- How they feeling about services been received from NHS? What they expect to receive?

Gaps in treatment

- How you think about other service can be more help from those organizations who involving in manage your condition.

Private /alternative treatment

- Who do you seen in privet sector?

Deal /future treatment / management

- What kind of interventions you may chose for manage you condition?

Probe:

- How? Would patients involved?

3.4.4. Data Analysis

'Framework Analysis' is a method of analysis used to facilitate data analysis by indexing relevant information, and liking elements and dimensions to develop categories that lead to the final theme (Ritchie, 2003a). The Framework method allows the researcher to gain an overview of the data, and determine themes to be used in the study. However, the framework method is flexible enough to also allow for new themes to be produced (Robson, 2011). The advantages of using the framework method is that it is suitable to answer specific questions, as it is very systematic, comprehensive and enhances the credibility of the analysis process (Srivastava, 2009).

As discussed in Chapter 3, for this phase of the study, the framework method is appropriate as it can answer specific questions regarding individuals pain experiences, daily living with chronic pain, and the process of management. In order to enhance the credibility of the findings, frequent peer checks of the developing themes was

conducted by the principal researcher, and the emerging findings were discussed with the supervision team.

The framework approach has a series of interrelated stages, as discussed in Chapter 3. The researcher began familiarisation with the data to recognise common themes, and to comprehend the data as an entirety, with the interview guide used in-line with the aims of the study, and the data gathered from the participants' transcripts. Following this, coding and development of a thematic framework took place. Similar subthemes were identified from the data index and grouped together under an initial theme. At this stage, the same process was applied to all data captured from the individuals' transcripts, with new themes emerging. Subsequently, this data was sorted by theme and summarised in matrix-based charts, while retaining the language of participants (Ritchie, 2003b). This helped to recognise the data as a whole, which is crucial for the subsequent development of themes (Ritchie and Lewis., 2003).

3.4.5. Familiarisation

The familiarisations process identified emerging themes within the data. SA read the transcripts repeatedly, and used a color-coding method to determine codes and themes relevant to the research questions. Familiarisation is the first step in the analytic process , in which the researcher gains an overview of the information coverage, and become thoroughly familiar with the data (Ritchie, 2003). This supports the construction of a thematic framework.

Figure 4.2 details the initial thoughts following a period of familiarisation. Capturing the lack of understanding by healthcare professionals, and the lack of support by both healthcare providers and communities to people with widespread chronic pain were the key findings of this stage.

- Participants had strong beliefs that GPs and professionals should be up to date regarding fibromyalgia diagnosis and management. Healthcare providers were deemed to not know much about the condition, to the frustration of people living with FMS.
- Self-finding is the process that involves the patient being independently able to access information. Participants often found information from such process unhelpful. Procedures to do this were discussed, which included internet, posture, support groups, GPs and rheumatologists.

Figure 3. 1 : Initial thoughts following familiarisation.

3.4.6. Thematic framework

The framework approach is considered flexible enough to allow novel, unanticipated themes to emerge (Ritchie and Spencer, 2002). Following familiarisation, the transcripts were reviewed line by line to identify codes, and group these into initial descriptive themes. Eight initial themes were devised from the data, where the first four participants' transcripts were reviewed line by line, and a thematic framework was developed. The emergent themes were discussed and peer checked with the academic supervisor. This framework was applied to the remaining transcripts in a process termed 'indexing' (Ritchie, 2003b). The thematic framework was flexible enough to allow new themes to emerge, which occurred over the course of the data analysis. Following completion of this stage of the analysis, new themes were discussed with the academic supervisor. The thematic framework, provided in Figure 3.2 , was developed and refined over the course of the analysis. The themes developed were relevant to the topic of the study, recurred across the data set, and were related to the research objectives.

One of the key points emerging was the individuals' views of living with pain, which included patients' experiences of pain, interventions, support and emotional aspects.

The lack of understanding and support of patients and their concerns also emerged from the familiarisation procedure, and developed the subthemes. Thematic framework. A chart per heading with sub headings was devised. Data was emerged from the original context, and rearranged according to the appropriate thematic

reference. Charting consists of the information drawn from the thematic framework (Ritchie and Spencer, 1994) The matrix-based charts of each theme involved in the charting phase included the sub-themes along the top, and each participant down the side. The charts included summarised data under each of these headings, to allow the researcher to get a 'feel' for the data in that theme and across participants (Ritchie and Spencer, 2002).

A data summary captures what the participants are frequently saying regarding their living experiences, while the researcher is making the data more manageable (Ritchie, 2003a). During the charting phase, it became clear that the main focus was on misdiagnosis, and being unclear if the symptoms were related to FMS, which caused individuals frustration. The psychosocial impact on daily living activities, and individuals being tired and exhausted because of the pain, fatigue, and unrefreshing sleep were frequently highlighted at this phase. Within this aspect of the analysis, the development of elements and dimensions was carried out. Elements were identified according to the underlying dimensions, to illustrate themes and to expend the experience of living with pain, in order to capture the relevant dimensions of the phenomena. Once the underlying dimensions were identified, the data had to be examined, and elements had to be combined into different responses to a set of categories that discriminate between different manifestations of the data (Ritchie, 2003).

Patient's experiences
1.1 Diagnosis
1.1.1 Previous diagnosis
1.1.2 Testing
1.1.3 Misdiagnosis
1.2 Pain description
1.2.1 Varity of causes of pain
1.2.2 Nerve pain
1.2.3 Constant pain
1.2.4 Worsening pain
1.2.5 Cope and self-managing
1.2.6 Memory impairment
1**.3 interventions**
1.3.1 Medications efficacy
1.3.2 Pain clinic
1.3.3 Physiotherapy
1.3.4 Massage
1.3.5 Hydrotherapy
1.3.6 CBT
1.3.7 Chiropractor
1.3.8 Acupuncture
1.3.9 Psychotherapy
1.3.10 alternative therapy/herbal/reflexology
1.4 Support
1.4.1 GPs
1.4.2 H C professionals
1.4.3 family/friends
1.4.4 NHS
1.4.5 Private
1.4.6 Resources
1.4.7 Attitude of HCP
1.4.8 Lack of support
Emotional aspects
2.1 Annoyed/angry/ increase stress
2.2 Depression
2.3 Anxiety
2.4 Fatigue/Tiredness
2.5 Unrefreshing sleep
2.6 Frustration
2.7 Frightening
Difficulties faced
3.1 understanding of condition
3.2 Challenging speciality (physiotherapy/Nurses/GP)
3.3 Fighting to referral
3.4 Disabled and loss of work
3.5 Resources availability
Patients concerns
4.1 Gps update
4.2 Need for specialist
4.3 public awareness
4.4 combination
4.5 Functioning/muscle power
Research
5.1 Further research
5.2 Funding

Figure 3.2 Indexed thematic framework

3.3.1.6. Developing Categories and Themes

Following the charting stage, which enhances the credibility of the data analysis process through providing a clear audit trail, categories were developed. The principal researcher explored the analytic steps of framework analysis to develop categories. Ritchie and Lewis. (2003) described the process of identifying categories, which involves exploring elements and dimensions to identify differences within the data. A set of categories that differentiate between the variability of the identified dimensions were devised. Data interpretation began the process of linking categories within the data, and developing a higher order themes informed by the developed categories (Spencer, 2014b).

Figure 4.4 illustrates the illness experiences, and the development of the journey to diagnosis. The same process was applied for the four figures below .Some overlapping between categories remained even at the later stages in the framework analysis, due to the richness and complexity of the illness experiences.

3.5. Findings

The main themes and subthemes developed through the analytic process revealed four linked higher order themes. These are the journey to diagnosis, coping with the variability and unpredictability of symptoms, the availability of and satisfaction with current healthcare practices and services, and the emotional influences.

3.5.1. Journey of Diagnosis

Participants were asked how they felt about the history of their symptoms and how they managed their condition. Participants discussed being misdiagnosed, and finding it difficult to explain the type of pain they were experiencing. Another area that was regularly raised was comparing FMS symptoms with other illness experiences. All participants unfavourably remarked that no or very little information was given to them following their FM diagnosis. All participants had their diagnosis confirmed by a secondary care specialist (rheumatologist), as FMS is hidden in uncertainty and lack of knowledge, and it is not easy for others to understand living with fibromyalgia.

Participants reported that physicians were unaware of how to perform the examination of tender points, due to the lack of understanding of their condition. Misdiagnosis was

frequently viewed as a cause of critical anxieties for people living with FMS. Commonly, the individuals living with FMS developed a self-strategy of coping with their condition, but were unable to manage flare-ups, because of the varied nature of the symptoms, which made it difficult for participants to describe their living experiences. The participants were asked about when and where they had been diagnosed, and different perceptions were highlighted concerning the diagnosis procedure. Generally, the participants had negative views about the support that people living with FMS received from the health services.

The participants also discussed their experiences of being misdiagnosed, and their concerns about the development of expertise understanding and management of FMS in UK. This appeared when patients debated their GPs and consultants, and found it difficult to be involved in the management of their condition, because of the lack of understanding of the cause of their pain. Furthermore, the participants described that they often asked to be referred to a consultant, as the primary care was unable to offer them something that could help to maintain daily living activates (DLA). Furthermore, the patients often chose not to go back to the GPs upon referral to a consultant, because of the pain severity and fatigue.

Figure 3.3: illustrates the development of this theme Journey to diagnosis. The diagram depicts the development of the initial themes from the thematic framework through to higher order themes. The elements, which capture the essence of patients' perceptions of living with chronic widespread pain, were then grouped into dimensions. Dimensions with commonalities between them were grouped into categories, and finally into the higher order themes.

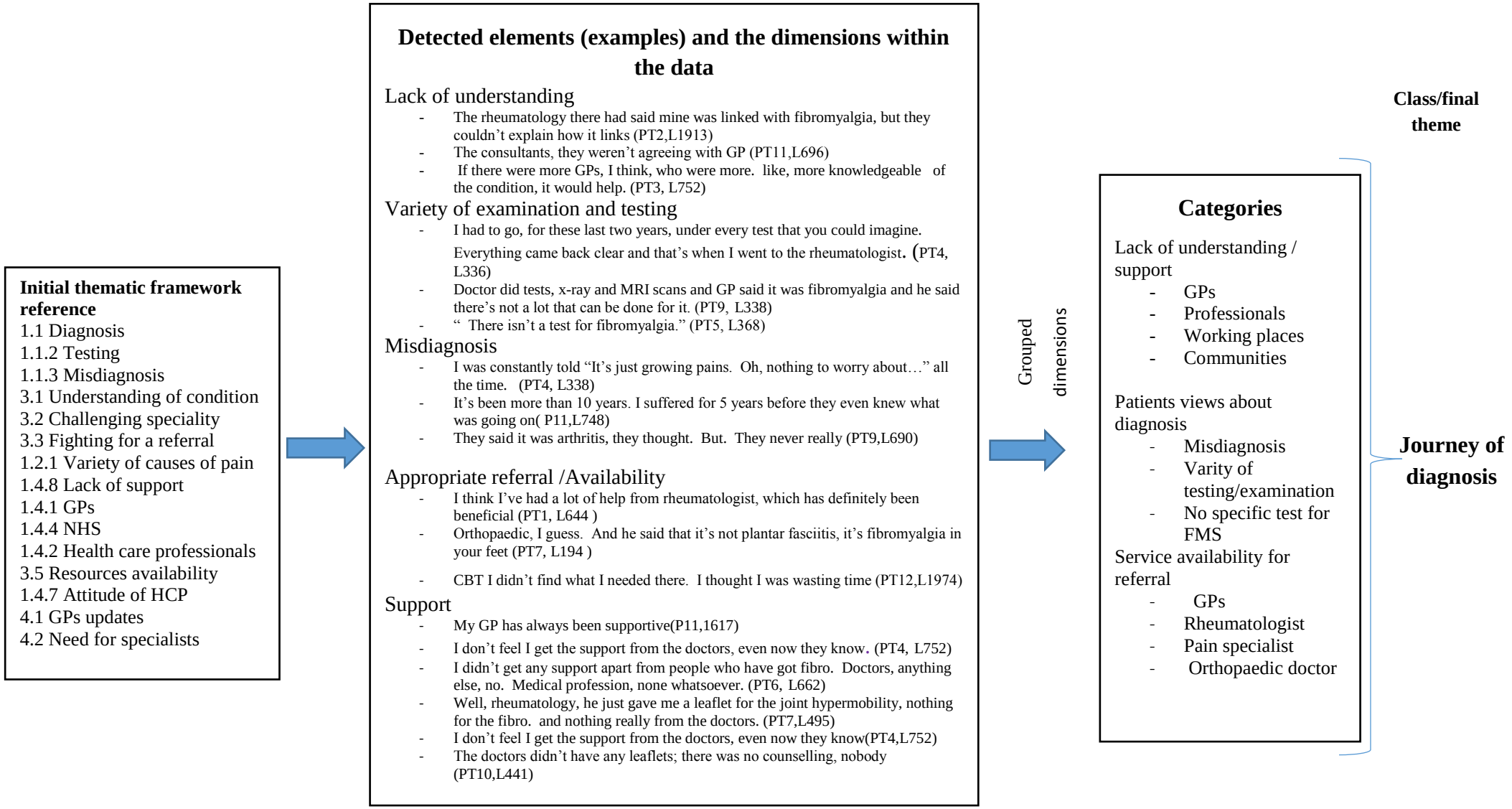

Figure 3.3: Development of the Journey to diagnosis' theme.

The overall concern identified by the participants when attending primary and secondary care and specialists was the misdiagnosis of FMS, because of the lack of understanding of the condition. The lack of understanding, misdiagnosis and support were elements that the participants considered to be significant issues in the context of the assessment and management of their chronic widespread pain. The availability of management and appropriate referral procedure were also highlighted by the participants as key aspects of the diagnosis process.

Eight out of twelve participants were dissatisfied with how they were treated by GPs, professionals and therapists due to the lack of understanding of their condition. These participants questioned how the misdiagnosis and understanding of pain features was linked to FMS. They also attributed misdiagnosis to the difficulties involved in treating their chronic widespread pain.

> PT2: I was misdiagnosed when I was a child in '83… Until 2011, I was misdiagnosed. And then re-diagnosed in 2011 with the fibromyalgia, arthritis. But they believe I've had it since the age of 4. And so that'll be 36 years of this.L185
>
> PT3: It's a bit of a learning curve. I think it's a bit of a learning curve for her as well. She doesn't specialise in it. Her speciality is, like, with skin. Like is dermatology. So it's a bit different.(L567)
>
> PT 4: PT4: I was constantly told "It's just growing pains. Oh, nothing to worry about…" all the time. The consultant *finally* wrote a letter to my GP to say it was fibromyalgia to treat that… They have nothing but respect for me now. They talk to me much better.(L410)
>
> PT5 : The GP didn't have any idea, the GPs don't know about everything. I mean, I've had other medical conditions in the past. (L275)
>
> PT7: I kept going there and GP's thought the plantar… And then I went in one day and he said ", you look ill. Tell me, from your feet up, what's the matter." And it was just pains, pains, and pains. (L361)
>
> PT11: I was referred to the hospital. They said that it was just… Is it hyperflexibility? I don't know the word. They were saying that my muscles were too flexible. I think it was something like that. I don't know the… Yeah, I think it was that. So, they couldn't do anything (L748)

Other observations concerning the person living with FMS being involved with such a variety of examinations, testing, and diagnosis processes were highlighted as experiences that the participants went through to assess their chronic widespread pain. They were left frustrated at not being able to access the appropriate healthcare service, and mentioned the variability of diagnosis processes frequently.

> PT1: Well, the doctor actually thought perhaps it's something else and sent me to see a consultant, which was when some extra tests were done. Actually the consultant did come up with a suggestion of some tests that the GP might want to make.(L324)

> PT2: I had numerous x-rays, scans, things like that, but… They were very dismissive even as a child .They've tested me for everything.(L214)

> PT3 After all the tests had been done, and then gone through just to rule out everything else. So, like, arthritis and stuff like that. And… I can't remember what else was looked for. And then it was just last year when I was starting to have, like, the MRIs. The scans. (L131)

> PT4: They sent me for hip x-rays, knee x-rays, shoulder x-rays, everything was coming back clear with tests and x-rays and things. (L169)

> PT7: I had to have an MRI and I had to lie like that in the MRI machine.(187)

> PT9: Doctor did x-ray… He did tests and he said it was fibromyalgia and he said there's not a lot that can be done for it, apart from trying to find a drug that suits.(338)

> PT10: All they did was blood tests and then, at the end, he just did the pressure points. They were doing all these blood tests for rheumatoid arthritis, something else.B – division (L402)

Another point discussed was the fact that the appropriate referral and availability of rheumatologists were often not accessible to FMS patients in the UK, even though the participants were referred by GPs to other healthcare professionals, such as pain specialists and physiotherapists. Waiting time was also a concern for people living with such chronic pain. Furthermore, the participants mentioned being caught between GPs and rheumatologists, and in some cases, being refereed to orthopaedics, as the GPs thought their presentation linked to comorbid conditions, such as neck pain or

low back pain. The participants were offered medication as treatment for fibromyalgia and fatigue symptoms, and some of them made positive observations regarding rheumatological management. However, a number of participants brought up negative memories regarding experiences of being constantly referred to different kinds of healthcare sites.

> PT1: To be honest, the waiting time from the doctor referring me to actually getting an appointment with the NHS was four months.(L595)
>
> PT6: I went to the rheumatology. Moreover, they said I had fibromyalgia, and they gave me a leaflet and said "You've got fibromyalgia. There you are. You are done. There's nothing more we can do for you." Then finding a doctor who believed in it, which was quite hard.(L342)
>
> PT2: It's just the attitude – especially neurologists, because I had to see a neurologist last year. And when they diagnosed the problem with my legs, they didn't want the word 'fibromyalgia' mentioned. They didn't want that word mentioned. And that was their attitude. "You don't mention that name. It does not exist."(L882)
>
> PT8 I had a pain management, and I am down to do a mindfulness – eight-week mindfulness course, through the NHS,(L966)
>
> PT10: the doctors at the hospital, the rheumatologist – although one of them was very nice to diagnose it – they didn't have the literature. They didn't. They just said "Continue with the cocodamol." And that was it.(L1000)

The invisibility of chronic widespread pain was an issue facing most of the participants. Furthermore, they reported a lack of compatibility between the pain, symptoms and other comorbid conditions. GPs and healthcare professionals observed patients physically, which was not mirrored by how the patients felt inside (i.e. with respect to physical appearance not matching the individual's feelings). The participants also described how the misdiagnosis of their condition was an additional difficulty posed by the healthcare system itself, due to the limited time available to see specialists. Long waiting lists in the sites of assessment and management of GPs, rheumatologists, psychologists and alternative therapists also emerged as a common theme. As such, many participants reported the need for a specific pathway that FMS patients can go through to obtain a correct diagnosis.

> T1: Reading a consultant report, that was when Gp then said "I apologise. You have got polymyalgia. I should have recognised it earlier.(L695)

> PT11: It's been more than 10 years. It took them 5 years to diagnose that I have this. I suffered for 5 years before they even knew what was going on. I was referred to the hospital X. They said that it was just… Is it hyperflexibility? I don't know the word. They were saying that my muscles were too flexible. (L748)
>
> PT2: The rheumatologist there had said mine was linked with fibromyalgia, but they couldn't explain how it links. (L207)

That fact that the aetiology of FMS is unknown makes it a hidden illness, which results in difficulties being faced by people having the condition. Furthermore, the participants frequently mentioned how challenging it was for physicians to diagnose the disorder in both primary and secondary care, the misunderstanding of the history of living with pain, and the varieties of FMS symptoms and how they linked with comorbid conditions, such as fatigue and rheumatoid arthritis. GPs and healthcare professionals were described as not confident in the management of FMS, and that it seemed they could not expose the quality of service offered to individuals. Most (7/12) participants blamed GPs and healthcare professionals for not providing effective intervention approaches, and not taking into account the unpleasant effects of the pharmacological treatment prescribed for their condition.

> PT2: The GPs just don't wish to know now. (L207)
>
> PT10: Doctors said "Oh, I haven't got a leaflet. Go and look it up on the internet." And that was it.(L441)
>
> PT4: I would say, with the doctors… I mean, they've not been horrible, the local doctors. But I've had to fight with them to listen, to believe me, to get me referred. (L525)
>
> PT5: The GP, you know, didn't have a clue about fibromyalgia, didn't have a clue about what my pain was. (L740)
>
> PT3: Obviously I've not heard back from the rheumatologists, but that's kind of how things go, apparently.(L525)
>
> PT7: Well, rheumatology, he just gave me a leaflet for the joint hypermobility, nothing for the fibro. (L950)
>
> PT8: There's no publicity in the GP's surgery or anything, Just like some kind of advice place that would tell you what's available, even if it is the NHS or medication, but give. (L1248)

The participants had a perception of a lack of support because of the misunderstanding and lack of knowledge of the natural course of the condition by both professionals and community sites. There were not any investigations performed on these sites, and services were viewed as not appearing to work together or not being linked.

> PT:12 I don't think I've had anyone who genuinely understands it and accepts that it's quite. It's not a serious condition in that you lose independence, but it's serious in that, you know, you're no longer able to do You're less functional than you used to be.(L2095)
>
> PT12: when you go to the specialist, they kind of think "Well, what are you doing here?" Because you're walking in and you're not obviously… You know. And they see people really, really poorly. Do you know what I mean? So you kind of feel a bit of a fraud. And then you come out and you've still got the same problems that you went in with. So you don't kind of get that help. You don't need highly specialised people in rheumatoid arthritis.(L2049)

The journey to diagnosis was highlighted as a challenge for both healthcare professionals and people living with chronic widespread pain, and was characterised with limited access to the healthcare system. The diagnosis procedure of fibromyalgia itself was unclear, as no standard process of diagnosing chronic widespread pain existed. The overall theme emerging from the discussions with the participants was that understanding the condition and gaining knowledge about it, are exclusive responsibilities for the GPs and specialists, regardless of resources availability.

3.5.2. Coping with variability and unpredictability of symptoms

The participants mentioned having numerous symptoms during daily living, with different pain severity. They also highlighted that they had difficulty managing, coping and functioning. This theme served to illustrate that the experiences of flare-ups of pain and symptoms is quite variable among the participants. The sub-themes that emerged from the data were grouped together to produce the final theme, as depicted in Figure 3.4.

The unpredictability of FMS symptoms, and the constant and worsening pain were highlighted by most participants. Furthermore, the variability of symptoms recurrences was behind the participants' concerns that the symptoms could affect their

daily living activities. In addition, they reported trying to cope with their pain, with varying degrees of success.

In addition, the participants were also concerned that the pain was taking over their bodies, and mentioned how this impacted their life, and their ability to cope with the severity of the pain.

The results presented here highlight issues such as the concerns around activities and functions, the impact of constant pain all over the body, particularly in muscles and joints, and the struggle to tolerate the pain. Figure 4.5 demonstrates the development of this theme.

> PT2: I mean, just sort of the pain you get is a variation of pain…It is really hard to say. It's so hard to say. Basically it's everything. Everything. Joints, muscle and bone.(L445).
>
> PT6: It can move anywhere. My hands are bad, can be bad. I don't know if... That's about it. It can be anywhere.(L231)
>
> If I've been walking a lot, it tends to be hips and legs. If I've been cooking or baking – hands and arms. So, yes, it just depends what I've been doing. I'll put arms in as well. Oh, the same intensity? it can be a little bit or it can be a lot where I can't move and I have to just stop and wait until it eases. If my hands are bad, they don't work, they lock. So I have to wait until they just loosen a bit and ease up. It could take about 20 minutes or so just waiting until they're loose and I can move them again.(L279)
>
> PT12: I just get muscle pain all the time, whenever I use my muscles. So it's just a case of not overdoing any muscle… And just keeping everything… Trying to release all the time…. So, if I do something else, like, there'll be pain in the shoulder. So it's kind of all over. All… Depending on what I've done.(L304)

The participants recognised the value of coping with the pain, and taking time to develop this ability. However, they reported that flare-ups made it difficult to cope with the pain. The participants also shared their points of views on how the pain could be managed, and what medications work best for the pain level. Medications were prescribed by GPs, and the participants were not certain of what helped with regards to the symptoms they had in that day. A few of the participants (3/12) pointed that medications were not beneficial for their condition.

> PT6: I had a major flare-up after the operation, where my bowel packed up, my bladder packed up… It was just horrendous, but… That's the pain we cope with. We get pain… Well, I get pain, it could be anywhere. One day it could be my arm, next day it could be my leg. It's obviously coming from my head, but I don't know what sets it off. So… So that… I find that is the hardest… Is the panic… And the pain. The rest I can cope with. (L167)

> PT7: I went back to the doctor and said "I cannot cope with the pain." And I explained, because it was a different doctor, that I was meant to be coming off the pregablin and he went "We can put you on tramadol – which I don't really want to do…" And I went "Oh, I don't really want to go on that either." "Or we'll try you on…" And it was this other medication, which I've tried, but I remember it made me feel sick (L654)

> PT9: I went to the GP and got the medication every month. And I was on them for maybe six, seven months. And I was doing fine. I was coping. Still in pain, but coping with it.(L783)

The participants reported that they were unable to function because of the pain severity and fatigue, as well as losing muscle strength. Performing daily activities and exercise was also highlighted as an issue for people with FMS. Furthermore, the participants discussed difficulties with movement during daily living activities, as can be clearly gleaned from the transcripts. The exercise approach advocated for people living of FMS was met with some annoyance by the participants, as they often felt quickly exhausted.

> PT6: I used to get so annoyed and thinking "Exercise! I can't function, never mind exercise!" Exercise works if you can get somebody who knows what they're doing L729

> PT9: I would sit in the chair and I couldn't do a thing after a swim. So, the doctor had said maybe half it, half your time – I used to do an hour and then I halved it to half an hour. Fine. I didn't find it hard, swimming for half an hour, for an hour. It was after I came home. I was exhausted L981

> PT9: If I go into a shop and I'm trying to get round, I'm sort of… If there's people everywhere, I don't like it. Because they tend to knock into you and you're sensitive to… You might…

> Someone might just think they're tapping you, but you really feel it sometimes, you know. So I like to try and have room to move around. I don't like crowds.L896

Constant pain was highlighted by the majority of participants. They felt such pain all over the body, particularly over the neck, shoulder, ribs, back and feet, and generally across all of the musculoskeletal system. The participants were unable to differentiate whether the pain was in the muscles or bone, and obviously felt the pain was quite deep. They described that the pain had become their life, where they had to work through it themselves, wondering what could be done to reduce it, and often feeling that they could not cope with.

> PT1: To be honest, it kind of comes in ups and downs and sometimes one symptom is worse. Restless legs was one thing that, at one point.L455
>
> PT2: It's just constantly there. You know, you wake up with pain; you go to bed with pain. And it's just excruciating pain, constantly. L153
>
> PT4: I said "I'm still tired. I've got pains, still" I was constantly tired. L 307
>
> PT6: I get constant pain in my shoulders and my neck, all the time. That doesn't go away. I get constant pain in my chest, all the time, and just under my arm – like as if you're having a heart attack, it feels like that. I get a lot of pains in my jaw. That's it, really. L193
>
> PT10: it doesn't feel the same pain. Fibromyalgia is a constant ache and a different pain. This pain is an ache in the joint. L399
>
> PT11: I don't know how to explain it. But the pain is mostly in my back neck. The back of my neck. Constant headache. Constantly, I've. L286,

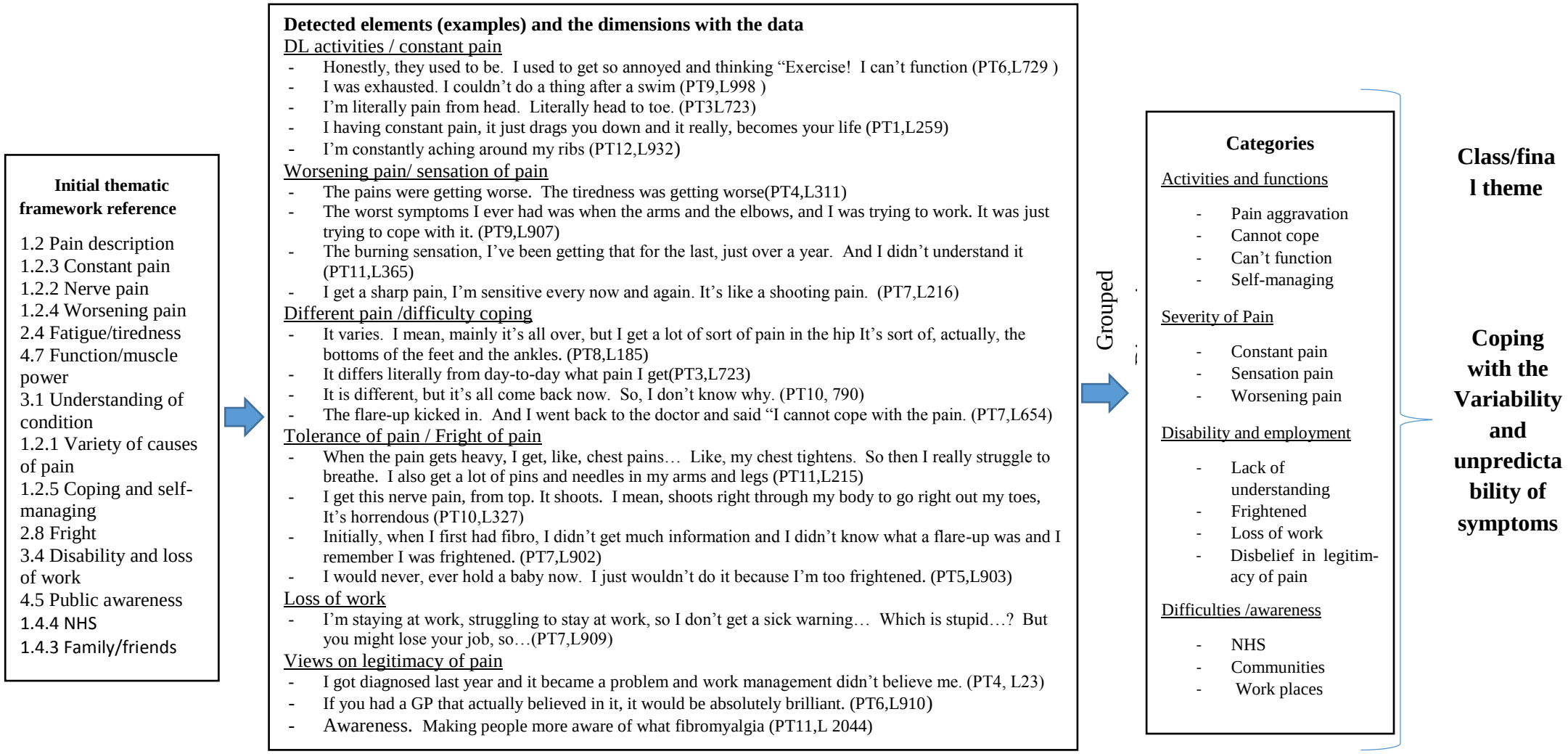

Figure 3. 4: Development of the 'Coping with the variability and unpredictability of symptoms' theme.

A common theme that emerged from the data was the worsening pain felt by the participants, and the loss of control over some aspects of their lives, as the medications were just taking the edge of the pain level off. The findings discussed below highlight the worsening pain, tiredness and difficulty functioning because of the pain severity. The participants experienced pain that affected every part of their lives. The results in this dimension (worsening pain sub-theme) showed that the participants' feelings of pain increased over time, as pain unpredictably evolved and progressed during the diagnosis journey.

> PT4: The pains were getting worse. The tiredness was getting worse.… I was at work. I was falling asleep at work. (L311)
>
> PT5: Worsening pain: things like a repetitive. Like knitting. If my hands will knit, I knit sometimes because just. It distracts and sometimes it can take my mind off the pain. (L581)
>
> PT9: The worst symptoms I ever had was when the arms and the elbows, and I was trying to work… It was just trying to cope with it. (L907)
>
> PT11: when the pain gets heavy, I get, like, chest pains… Like, my chest tightens. So then I really struggle to breathe. (L234)
>
> PT12: The worst symptom is just back pain, probably, I think. Back pain and weakness. It's the weakness, I would say. (L1593)

Whilst all participants expressed a sense of loss of daily living functions, the quotes below demonstrate that some of the participants (6/12) developed acute nerve pain, and expressed concern about the sharp, shooting and burning nature of the pain, and how such pain impacted every part of their lives. Furthermore, the participants didn't understand the pain, as no information was given to them regarding nerve pain, and how it might affect their lives.

A number of participants described the varying experience of pain, in terms of the different types of pain felt, and how such pain differed from day to day. Furthermore, they reported a variety of symptoms related to pain in all joints and muscles, and described how they were unable to cope with their pain and with daily living activities.

> PT1: I think I would have gone mad by now. With the pain and with the… Well, with the pain… Because it would affect absolutely every minute of my life.(L551)
>
> PT2: Because of this I've been left 80% paralysed of the legs. You know. And you don't want to see people like that.L767
>
> PT5: One day when I couldn't walk. I mean, I could just about get round my flat holding on to the furniture, but I couldn't go outside, I couldn't... Everything hurt.(L488)

The participants believed that the tolerance of chronic widespread pain was an issue influenced by psychological factors, and that their concern regarding the lack of information contributed to aggravating their pain. They felt frightened to get involved in any of the daily living activities, or struggled to do so because of the pain they felt in every part of their bodies.

> PT1: Annoyed, more than anything else, that I'm actually somebody who has got this. It has such a big impact on what I can do, when I can do it and I think mostly I'm just… Well, I was going to say angry(L238).
>
> PT6: I can just be driving along and all of a sudden I get an anxiety attack or a panic attack. It's just… At night, it's like fright and flight.(L577)

At the time of the interviews, about half of the participants were unemployed due to anxiety and distractions caused by the chronic widespread pain and other FMS symptoms. One of the participants was employed, and felt she was able to continue with her paid job, while another was disabled because of the misdiagnosis of her condition, and was unable to work, despite having support from family to manage DLAs (see Table 4.3). With regards to their abilities to do work and perform daily living activities, the participants reported trying to engage in work, but finding the process challenging due to the lack of understanding of their condition in the workplace. In addition, due to the unpredictability of the symptoms, the participants reported a lack of understanding by employers at times.

> PT3: I would really like, for more people to actually be more understanding of it. Because not everybody knows. And I'm kind of thinking, like, the government do need to step into things. And put into the workplace.(L835)
>
> PT5: it seems like being honest with them, there's no understanding in the workplace for fibromyalgia. There isn't anything out there. Not that I know… Especially in the workplace. I think work… Big workplaces need to be aware of it… Because it's a hidden disability and… Just because it's hidden, people judge you. (L752)
>
> PT4: I go back for the second interview, in the actual department that I'm applying for… "Oh, you've done really well… Now to ask you, have you got any disabilities?" So you just say "Fibromyalgia."What's that?" Then you tell them and you say "Well, I've got medication to control that…" You get a letter in the post saying you haven't been successful.(L271)
>
> PT6: Half of the people with fibro don't work, because they cannot work, because they cannot function. (L742)
>
> PT7: So I'm staying at work, struggling to stay at work, so I don't get a sick warning… Which is stupid… But you might lose your job.(L909)

The participants described how they were questioned at times about whether they genuinely had been ill and suffering with pain by people at work, and even by GPs, as a result of physically looking well. The described how such an experience was frustrating for them, as they could not describe or explain more about the phenomenon of their disability. In addition, the majority of participants felt that it was a challenge for them to express how the lack of knowledge among healthcare professionals and communities was affecting their DLAs .

> PT4: I got diagnosed last year and it became a problem and work management didn't believe me, they had issues with me having appointments and things like that. (L23)
>
> PT6: Even if you had a GP that actually believed in it, it would be absolutely brilliant.(L910)
>
> PT11 Awareness. Making people more aware of what fibromyalgia is. Because, I find, like even at work… Whether at work of social, you know… When I'm in a social, sort of, place… People don't understand what my condition is.(L2044)

The participants also highlighted issues such as coping with the variety of symptoms, having difficulty managing functional activities and coping with pain, the pain taking over the body, and the impact of symptoms on daily life. Furthermore, the participants pointed out that medications were not beneficial for their condition. They also found it challenging to convey how the lack of knowledge among healthcare professionals, communities and workplaces was affecting their DLAs, which at times, made them unable to continue with paid work.

3.5.3. The availability and satisfaction with current healthcare practices and services

The interviews with participants illustrated that the lack of understanding of the disorders was reflected on the therapeutic approaches prescribed, as individuals noted that the interventions and treatment must be individualised. A key focus of the discussion involved the varieties of interventions that the participants encountered, their availability to people with FMS, and the participants' beliefs reading the interventions' efficacy. Furthermore, the challenges the participants faced due to the varieties of intervention approaches, their availability for the management of their condition, and the inappropriate referral procedures were highlighted. Figure 3.5 illustrates the developments of this theme.

The participants also expressed their views on attending various health services, and on the limited availability of access to the NHS services. The participants had specific individual views regarding how this long-term condition influenced their everyday lives, and their experience of contact with primary and secondary care. Moreover, the need for a specific programme for FMS was discussed.

The participants who had experienced several intervention approaches felt that each intervention did not work independently. Medications such as gabapentin, pregabalin and duloxetine were thought to work in combination in some days, and not in others. Furthermore, the participants also found the cost of some interventions a barrier, such as massage and chiropractic intervention, as these interventions are only available in private care, which in many cases was beyond their means, and made them feel helpless to cope with their condition. The following sub-theme (efficacy of

interventions) details the participants' views on the interventions' availability, and their satisfaction with them.

> PT1: The medication hasn't much changed other than the steroids that I was taking for the polymyalgia, which was the thing that would take that pain away, but there isn't anything that takes the fibromyalgia pain away. Similar painkillers for both. Similar anti-depressants. (L308)
>
> PT2: painkiller. They didn't really do any good. Painkillers don't seem to… They don't, like, take the pain away. It just takes the edge, sort of thing. (L513)
>
> PT5: just taking something like Paracetamol didn't help, so I had to learn to... I got other painkillers, but I just had to learn to, if the pain was very bad. I've been through a lot of different tablets, painkillers, Duloxetine. Yeah, it's a mixture. I tried Gabapentin and that didn't work so I tried Pregabalin and that doesn't work by itself, but it works with other things. Duloxetine is one and some Codeine, to find the right ones and I think now it's probably the combination that helps the most. (L516)
>
> PT1: The medication some days it works better than others. I don't know (L321).

Complementary therapy as a combination was reported to provide the participants with some help. The participants thought massage, graded exercises, and hydrotherapy could help if those who performed these approaches had the knowledge and skills, because they felt the majority of the pain can come from the muscles tension. Moreover, this element of combination and use a load of different interventions, like exercise and massage with force, again, made things worse. Other than that, nothing helped with symptoms and pain.

> PT6: The massage and doing the hydrotherapy that is going to work absolutely brilliant. For me personally. We get a discounted massage after. If we could get that on the National Health, it would be absolutely brilliant.(L757)
> T8: we have to get massages through the support group privately which really, helped.(L 826)
> PT11: I went to see a chiropractor privately, it did help, but I couldn't afford it. Because of my condition I had to leave work, so I… Yeah. Because back then I was working more hours; I was getting paid more I've seen a chiropractor Yeah. That helped, but the cost was too much. It's too expensive, yeah.(L1193)

> PT10: Acupuncture wasn't working at all and I knew straightaway it wasn't working at all .(L1092)
> PT6: Exercise works if you can get somebody who knows what they're doing. If you go to an exercise class, you've got to keep up with people. Nothing worked, then you'd be back to square one again. (L 736)
> PT8: Nothing works, but it is not fair. What else? Not a lot really. I had a pain management, and I am down to do a mindfulness – eight-week mindfulness course, through the NHS, I think they should try and go a bit more alternative. Maybe stuff like massages. (L 966)
> PT11: They sent me to a physiotherapist. The physiotherapist gave me some exercises. That didn't help. Because the physiotherapists said they couldn't do anything with me; they said they couldn't help me (L759)
> PT12: I can't think of anything that privately is available that would be helpful. And I'm really pleased that they're offering acupuncture on the National Health. (L 2478)

The pilgrimage from one intervention to another was an experience reported by most of the participants who were in search for a treatment to reduce their pain and make them feel better. The participants reported trying different approaches, none of which worked effectively for their FMS symptoms. Thus, healthcare professionals were viewed as lacking in the knowledge required to enable them to prescribe effective treatment, which may be due to the limited recourses and collaborative research undertaken in the UK. Furthermore, it was highlighted that not all GPs and specialists applied the same criteria to treat the chronic widespread pain of FMS. Because of the participants' dissatisfaction with the aforementioned issues, their relationship between healthcare professionals was sometimes strained. The participants also mentioned their frustration regarding the number of specialists they had to consult, as they were frequently passed from GPs to other healthcare professionals, which made finding a solution within the primary and secondary care systems more difficult.

In addition, the participants highlighted that they felt they needed a specialist for their condition. It was also felt that GPs and healthcare professionals needed to update their knowledge to develop a proper understanding of the condition. Furthermore, the participants thought that they would not benefit from prescribed medications and interventions approaches. The lack of understanding of the condition by healthcare professionals was cited among the participants as a key problem, especially when contrasted with other illnesses having specialist sites and facilities available.

> PT3: The GP doesn't specialise in it. Her speciality is, like, with skin. Like is dermatology. So it's a bit different. When I went back, for the follow up appointment after all of my referrals – she did say, "Right, well, here's one piece. One piece of information that I know." (L 641)
>
> PT6: Exercise works if you can get somebody who knows what they're doing. (L736)
>
> PT10 Doctors were all very, very helpful. Really helpful. They didn't know enough about it either,. They didn't have the knowledge. (L612)

The participants also reported that they been referred to Cognitive Behavioural Therapy (CBT), and described their experiences as being time consuming, and having left an impression of a lack of understanding of their condition. Specialists argued that multiple factors may be combined with such a condition, such as psychological factors, which upset the participants Due to these issues, as well as to being distressed by the therapeutic technique, and viewing it as unhelpful in the management of chronic widespread pain, the participants attempted, at times, to avoid going back to CBT.

> PT4: I mean, I've had CBT… Cognitive behavioural therapy, they've sent me for. I said "I think I'm right and I think you're wrong." And he argued black and blue with me to the point that he made me cry and he turned round and said "What are you crying for? I'm right. You're wrong. That's why you're here." And I walked out and never went back but never again will I go back for CBT because it's upset me." In fact it's made it worse (L562)
>
> PT7: I think those therapies; all the therapies are good, apart from maybe the CBT.(L1420)
>
> PT12: I have been referred to cognitive behaviour through to the pain clinic, it was just about writing down emotional things all the time and I really didn't feel that that was relevant. I thought I was wasting her time, you know, really She was looking into my psychological wellbeing(L777)

On the other hand, some participants highlighted that CBT was beneficial, especially when the professional focussed on how people can manage living with this illness.

> PT1: The GP did refer me for CBT twice, because the first time. It did help. it helped, because it just then focussed on "How can I live with this? I've got to live with this, so what can I do to help myself?". It was good and it's certainly something that I would ask to return to in the future if I felt I needed it again. (L412)

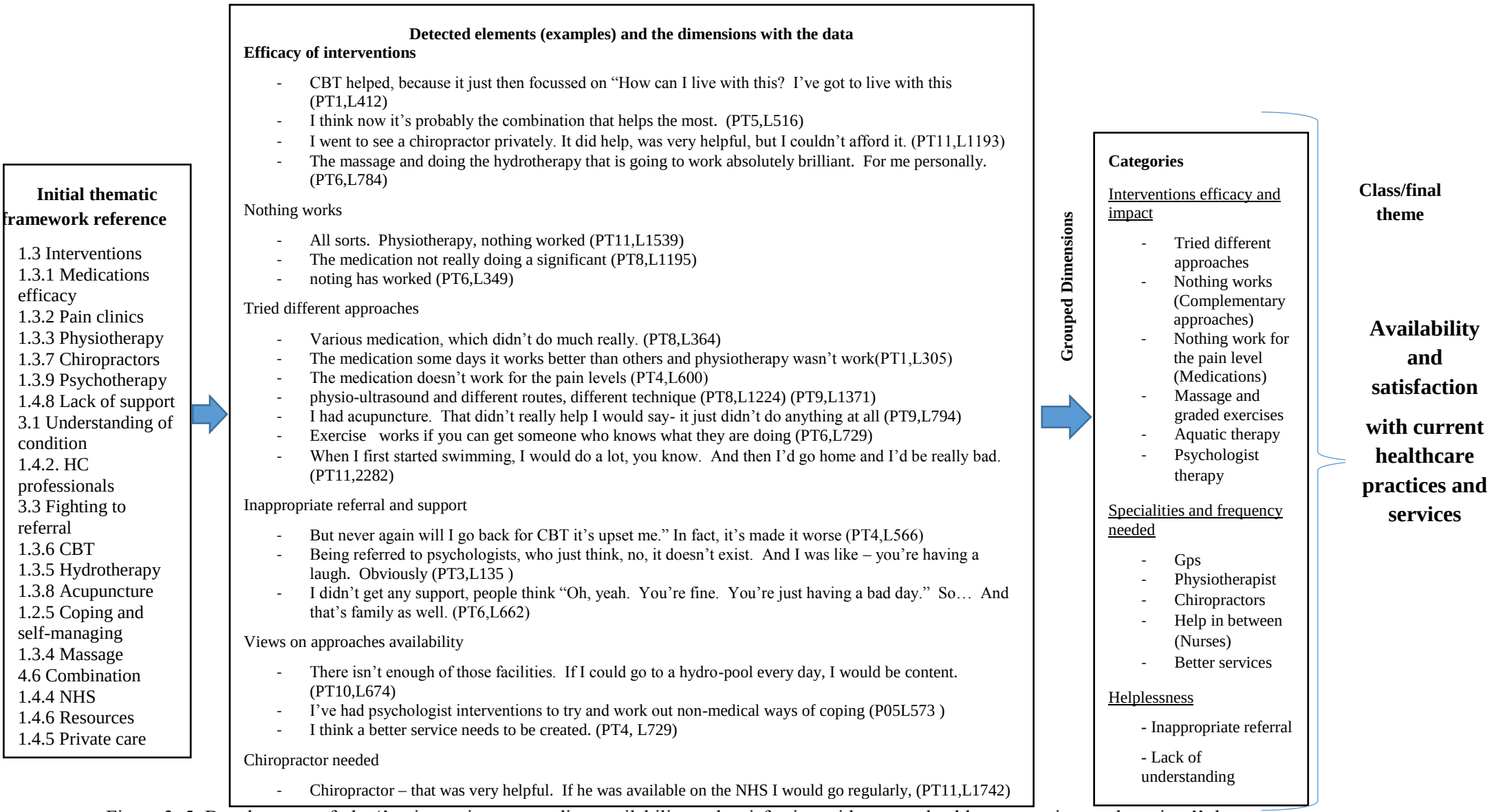

Figure 3. 5: Development of: the ''patients views, regarding availability and satisfaction with current healthcare practices and services'' theme

Moreover, a small number of participants highlighted that psychologists were helpful in combination with other approaches, while another participant mentioned that the psychologist she visited did not believe FMS existed, even though people with FMS had psychological issues, as is highlighted in more detail in the fourth theme.

> PT5: I've had psychologist interventions to try and work out non-medical ways of coping. So things like mindfulness, relaxation techniques, including just relaxing in a comfortable position with or without music or with or without trying to do a self-hypnosis thing in my head – talking myself into it.(L537)
>
> PT3: Being referred to psychologists, who just think, no, it doesn't exist. And I was like – you're having a laugh. Obviously (L135)

The participants believed that the lack of support was due to a lack of understanding, which influenced the services provided, and impacted their decisions not to go back to the specialist. The understating of the condition was considered the biggest challenge facing physicians and healthcare professionals, and contributed to the dissatisfaction of the intervention approaches offered to people with FMS. In addition, the participants mentioned being disappointed with the quality of care, and the procedures provided in the NHS, and felt that their condition was not cared for at the same level as other illnesses. Furthermore, the participants discussed how their social lives were compromised, as a result of the invisibility of the condition, the disbelief of other people of the severity of pain they felt, and being judged by people because they appeared physically well.

> PT4: Totally disagreed with the therapist I had. He asked me a question and I told him the situation and he said that I was in the wrong and that his idea was right. (L562)
>
> PT3: Psychotherapy: Being referred to psychologists, who just think, no, it doesn't exist. And I was like – you're having a laugh. Obviously.(L 135)
>
> PT6: I didn't get any support, people think "Oh, yeah. You're fine. You're just having a bad day." So… And that's family as well. (L662)

Following further discussions regarding the need for a chiropractor, the participants felt that chiropractors helped with the management of their condition. However, the participants raised the issue of costs, and not being able to offered the therapeutic

technique. Chiropractic and osteopathy were used as separate services to improve musculoskeletal disorders, and were reported to have positive effects, which made the participants question their unavailability in the NHS.

> PT11: I've seen a chiropractor Yeah. That helped, but the cost was too much. It's too expensive, If it was available on the NHS *I would go regularly*, you know. *If massage and chiropractor were available*, I would probably go for those two if he was available.(L1743)
>
> PT3: I've had chiropractor, I've been seeing a chiropractor for about four years on a regular basis for four years now, which helps. So I'm happy to actually stick with going to see chiropractor (L747)
>
> PT12: I paid for chiropractor I've paid for those before. And what's the other type of back specialist? .I've had an osteopathy, yeah. But there's nothing structurally wrong with my back. It was just to help the muscle pain.(L2471)

Understating the condition and the associated pain was seen as essential for the management of the condition, and for offering interventions that could support patients with FMS. The participants discussed feeling anxious about the services provided, both in primary and secondary healthcare, as they described how the interventions and support they received made them feel unvalued and helpless. The participants found it difficult to access the required level of services.

> PT4: if I want anything about it in between, going to the doctor's "No, you're under rheumatology. We can't help you." They're doctors. They should be able to help you in between. But, no… Hospital service, fantastic. For my psoriasis, arthritis, rheumatologist – fantastic. Doctors… Unless it's not to do with my condition, it's about something else, yeah, great. (L832)
>
> PT10: The doctors will give me anything I. If I say "I think this might help," they would give it to me, because, as I say, I don't think they've got all the knowledge. They are supportive. But they don't know. There's no treatment … There's no answer. Doctors can say "Right, that" When I go to the doctor's some of them say "Well, that could be fibromyalgia," but it might not be. (L 831)

Other points of view expressed by the participants included the accessibility and availability of services, their experiences of the diagnosis processes, and the efficacy of interventions they had. Most of the participants (9/12) highlighted that some

facilities had to be developed and available in the NHS, so that people could get access to them easily, especially if such services proved to be supportive and helpful for treating their condition. Some participants strongly expressed the need for their views to be considered.

> PT3: I think there should be more funding towards things like this. So that help is available for people. Not disability benefits, but… Like mobility if there were more GPs, I think, who were more… Like, more knowledgeable of the condition, it would help. (L 572)
>
> PT5: but I know people don't get that support and help, so I think more information would be good. Some GPs I know don't believe it, believe in it.(L843)
>
> PT8: There's not much information as to what's available. Even support groups, you have got to go and find them yourself on the internet. There's no publicity in the GP's surgery or anything, Just like some kind of advice place that would tell you what's available, even if it is the NHS or medication, but give you alternative therapies, you know. 1247 It just knows what's available really, is the hardest thing.(L1448)
>
> PT10: Only from home. From the internet. The doctors… As I say, he didn't have any leaflets; there was no counselling, nobody… That was it… "You've got fibromyalgia. Go and look it up on the internet." And that's all I got told.(L565)
>
> PT4: It's bad enough suffering chronic fatigue without a tablet that adds that extra tiredness on top. But I would like, if physio is the answer to help with things… I think a better service needs to be created. (L 727)
>
> T6: Nothing. They've given me no. Nothing for my fibromyalgia whatsoever.(L809)

The participants expressed that the service availability for people living with fibromyalgia gave them a feeling of helplessness, due to the effect that the pain had on them, and the difficulty of obtaining a referral to an appropriate healthcare professional. The issue of referral to the right professionals was debated in the line with providing chronic pain education. The participants mentioned being distressed because healthcare providers were not prepared to provide a range of interventions, or prescribe how to effectively use the service they already had. The link between the misunderstanding of pain and the effect of the condition on daily functions was also highlighted by the participants.

> PT1: NHS-wise, useless. Because, the staff that at the hospitals, it isn't nice. They treat you as if you are a malingerer. And they just don't want to know, through lack of understanding. Because of your condition, there's nothing more we can do."(L670)
>
> PT4: I don't feel I get the support from the doctors, even now they know…. They've got the official information from the consultant.(L746)
>
> PT2: I've never been given any professional support or anything. You know, you're sort of told "This is what it is. We don't know exactly what causes it, why it's doing what it's doing" but you're just sort of being told to get on with it really.(L496)
>
> PT5: I mean it would be great if all this just came from the GP. Maybe that's not realistic, but it should... it should come without too much of a fight for people.(L1025)
>
> PT6: I would like more support from the doctors, more understanding, because that would help our condition a lot – with the stress, because that gives you anxiety. Maybe a clinic that's just for people with fibromyalgia. Something like what other conditions have got, which we haven't got… Where you can actually go and they understand you. (L628)
>
> PT7: Nothing really from the doctors. A new doctors said I will go on-line for you, and I will have a look and see what they are doing in America." Because obviously, they lead the way, in America, for fibromyalgia, so hopefully he will dig something out. I do not know. However, I think I will be more supported at my GP now. Definitely, with the new doctors.(L714)

The findings above indicate the limited availability of intervention approaches and access within the NHS for individuals living with fibromyalgia. They also highlight the participants' dissatisfaction with the diagnosis processes and interventions efficacy, and their frustration with the variety of approaches being tried. In addition, the participants highlighted the need for a specialist for their condition. CBT was referred to as useful by some participants, however, others felt a 'hands on' approach was required. Throughout this theme, a clear dissatisfaction with healthcare services can be detected, as well as the wish of the participants to contribute to service design for this condition. The resulting lack of support was due to a lack of understating of the condition, which influenced the quality of services provided.

3.5.4 Emotional Influences

The following theme, deduced from the participants' views and experiences, highlights the fact that FMS has a psychological and emotional impact on self-identity. Emotional features appeared to affect the participants' daily living, and some participants felt they were emotional during the journey of diagnosis and pain management procedures. Moreover, they pointed out some of the hurdles and issues in both healthcare communication and social activities. A number of participants avoided contacting a health care professional, and even attempted to avoid or minimise social interaction with family and friends, as it was deemed frustrating for them not to be believed regarding the severity of pain they were suffering.

Psychological issues were reported by a number of participants, who often felt depressed because of the misunderstanding of their illness in healthcare, community and work places. The participants questioned themselves at the time of pain regarding credibility, and often felt frustrated by the lack of understanding of their condition. In addition, some of the participants reported that the aforementioned experiences contributed to the loss of their jobs. The participants also mentioned how they struggled to explain to healthcare professionals how the pain and fatigue influenced their lives, which amplified the chance of anxiety and depression. Furthermore, some participants highlighted that professional care, such as CBT, was focused on their psychological stories, rather than how the condition affected their daily lives. The lack of understanding was most clearly seen in the absence of relationship between the patients and healthcare professionals, which led to a lack of an appropriate support for FMS.

> PT4: Really depressed. Because of this, I've lost my job. Well, not because of it, but because there is no understanding out there, in the workplace. I've lost my job. (L 207)
>
> PT9: That was the bit where… It came to the point where I knew, when I couldn't manage my job, that I went into depression – I started suffering with depression.(L573)
>
> PT11: it upsets me… Because I don't have control of my own life. Yeah I feel depressed, when I struggle to do something, like, in the house… I get depressed because of it .(L614)

> PT12: I can understand it, because if you go there and… If you're in pain and you feel down, you can be dragged down. I think they were just trying say "We understand why you're depressed, but it will add to your pain." So, you know, this is… "Let's look at your mind as well as your body.(L728)

The participants reported the presence of emotional influences such as anxiety and depression. They also mentioned how tiredness affected their ability to manage their daily living activities, and made performing simple functions and tasks difficult, due to sleep disturbance. Most of the participants reported that they had a good relationship with healthcare providers. However, they pointed out that the lack of support and understanding of people with fibromyalgia by GPs and HCPs led to anxiety and depression. In particular, the participants felt distress and anxiety as a result of the lack of understanding of how the pain influenced their psychological and social wellbeing. Figure 3.6 details the development of this theme.

> PT8: I was so agitated at the time, I thought, the sort of anxiety symptoms. I got to the point where I couldn't even do my job. And I thought there was something wrong. I was going to work – I was shattered because I… I'd sort of go to sleep wide awake and woke up tired – like exhausted – and just couldn't concentrate (L405).
>
> PT4: Anxiety attack. Well, I don't suffer from anxiety… And I went to the doctor's and he said it could be your fibro again. I felt like I… It was just dead tight and I couldn't breathe (L205).
>
> PT6: Anxiety. I get a lot of panic attacks. Just, yeah. It can be anything. It can be anything or nothing. I can just be driving along and all of a sudden I get an anxiety attack or a panic attack. It's just… At night, it's like fright and flight. (L565)
>
> PT9: I suffer with anxiety and Doctor gives me I think, it was these little, tiny red tablets, I think, I mis-something they were… I can't remember the name. But he gave me a month's worth and he said "Try those." And I took them for a couple of weeks at home, but they just… They were really bad. I couldn't get off to sleep at all. (L189)
>
> PT12: I was anxious at not completing and doing everything I wanted to do in the day.(L824)

Furthermore, some participants reported sleep disturbance, and unrefreshing sleep, which affected their daily living activities. However, their often healthy physical appearance appeared to undermine the extent of their symptoms and suffering to the general public. The participants also reported experiencing loss of function

due to the nonrestorative sleep and fatigue, which, in many cases, impacted their employment.

> PT1: not being able to sleep. You feel absolutely useless during the day, because it's an effort to stand up and walk from one room to the other and then you go to bed on a night-time and you cannot sleep.(L430)
>
> PT3 I literally I struggle to get to sleep.(L717)
>
> PT4 It's horrible… And it's lack of sleep, as well. (L286)
>
> PT6 I couldn't sleep. I used to be awake all night. I would just get pains all the way through my body but they kept saying "It's all in your head. There's nothing wrong with you." Because then they didn't know about fibromyalgia I couldn't sleep… And not being able to sleep… For years… Because there was no medication that they would give you.(L327)
>
> PT8: I just need something at night to help with the sleep.(L772)
>
> PT9: I don't seem to be able to sleep, although I'm shattered. (L459)

Tiredness was commonly experienced by the participants. In addition, the participants also mentioned that the severity of pain during the day could be exacerbated by the unrefreshing sleep, which worsened the impact of the pain on their daily functions. Furthermore, they described how they struggled to sleep because of the chronic fatigue, and that despite taking medications such amitriptyline, they still felt tired and anxious. They also noted that the lack of physical energy prevented them from performing daily activities, and made them avoid socialising.

> PT1: The tiredness. You feel absolutely useless during the day, I think that kind of impacts as well on the depression (L261)
>
> PT3: The chronic fatigue. Because I'll have days where I literally I struggle to get to sleep. It almost gets to the point I can't get out of bed because I am so tired. (L348)
>
> PT4: The chronic fatigue is horrendous. It's really… It's so bad that, the fatigue, because, yeah, it's painful – the pains – and… I was just left to deal with it, if something could just say to the brain "You're staying awake until I tell you you're going to sleep." But there's nothing for chronic fatigue. It's bad enough suffering chronic fatigue without a tablet that adds that extra tiredness on top. (L289)
>
> PT5: Tiredness? Yes, and people don't believe how tired you can possibly be.(509)

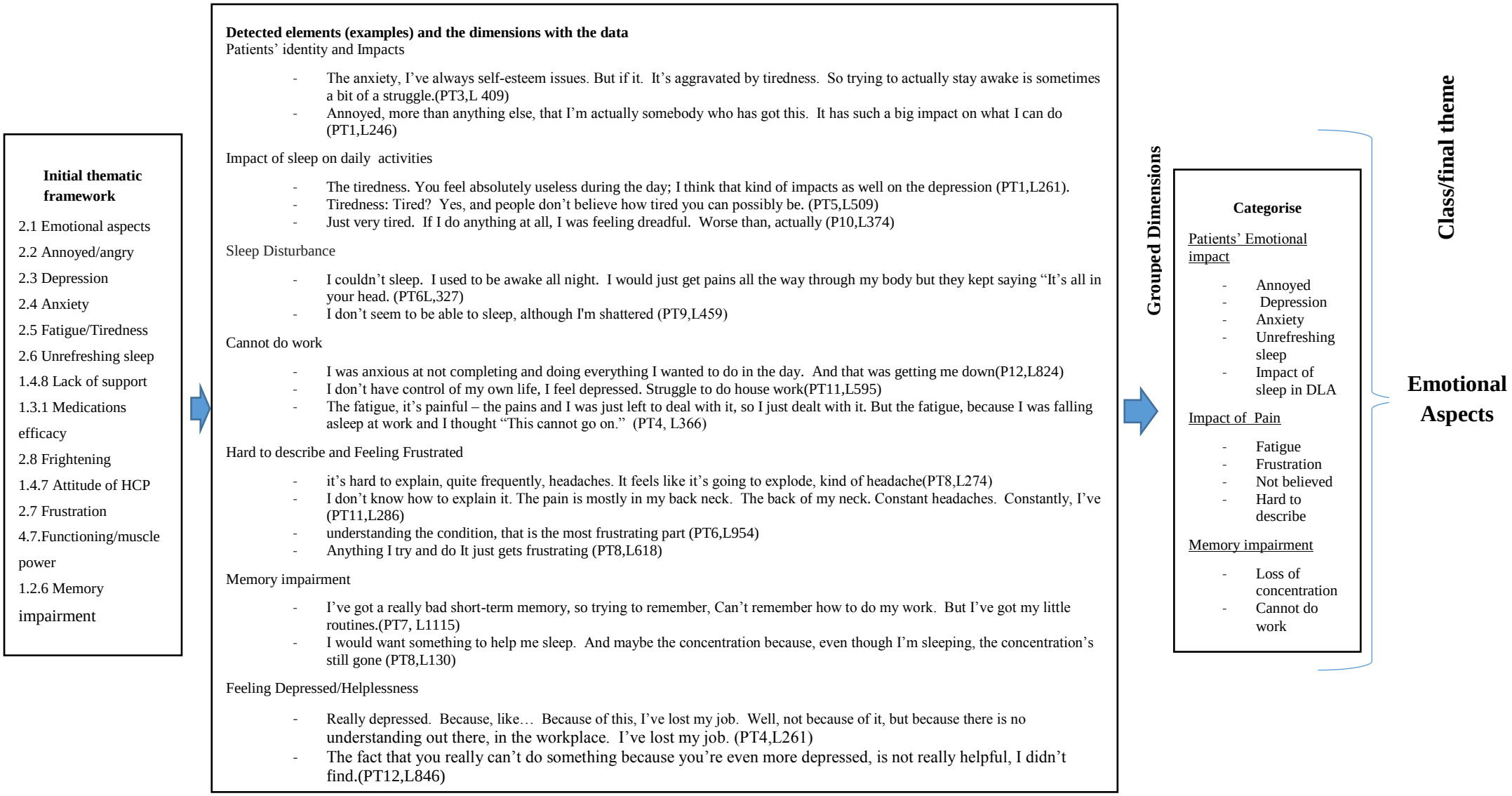

Figure 3. 6: Developing of the 'Emotional aspects 'theme

> PT8: I don't know. I was so agitated at the time, yeah. Yeah, it helped me sleep, but it didn't do a lot for, I thought, the sort of anxiety symptoms. I got to the point where I couldn't even do my job. (L405)
>
> PT10: Just very tired. If I do anything at all, even, you know… We've bought a hoover that's a hand-held hoover… I could hoover the living room. I was feeling dreadful. Worse than, actually, before (L374)
>
> PT11: I feel like I drain from energy, physically… I can't do long drives now. It just feels like I'm exhausted by the end of it. (L730)
>
> PT12 I was, you know, tired and exhausted. Prior to that, my thyroid had packed up, so I had hypothyroidism… So that was completely reduced, so that's aching muscles, fatigue, all that stuff.(L904)

The participants reported tiredness, anxiety and depression as factors that prevented them from managing DLAs, and being able to work. They also described the difficulty they had in functioning and controlling their lives, and mentioned struggling to even do simple housework.

> PT4: The fatigue… Because I was falling asleep at work and I thought "This cannot go on." (L547)
>
> PT11: it upsets me… Because I don't have control of my own life. Yeah I feel depressed when I struggle to do something, like, in the house… I get depressed.(L595)
>
> PT12: I was anxious at not completing and doing everything I wanted to do in the day. And that was getting me down. So they did say "Accept it. Organise yourself. And do these two things…" And that helped. Pacing yourself.(L824)

Another viewpoint that the participants shared was that they felt they needed to understand their condition after the journey of diagnosis. In addition, the participants mentioned feeling unable to describe their condition, which often made them feel frustrated. Unhelpful beliefs regarding their experience of pain among healthcare providers as well as communities was also highlighted as a common issue they struggled with. The participants expressed that, in addition to the lack of knowledge about the condition, such beliefs were also a result of people only focusing on their

physical appearances. The participants mentioned attempting, and failing, to change such viewpoints about their condition, which often left them feeling frustrated and helpless.

> PT8: It's… Oh, it's hard to explain… It feels like it's broken. It's kind of like that kind of pain. (L287)
>
> PT6: There's just obstacles in our way all the time. And just not understanding the condition. That is the most frustrating part. I think if we had that it would be half the battle.(L954)
>
> PT3: Being referred to psychologists, who just think, no, it doesn't exist. And I was like – you're having a laugh. Obviously,(L135)
>
> PT6P: I got medical help as soon as I went to the rheumatology. Moreover, they said I had fibromyalgia, and they gave me a leaflet and said "You've got fibromyalgia. There you are. You are done. There's nothing more we can do for you." Then finding a doctor who believed in it, which was quite hard – a GP.(L342)

Another experience that the participants described was memory impairment, where they highlighted the difficulty they had to concentrate, remember things, and perform daily living activities and tasks in their work.

> PT7: I've got like a really… I've got a really bad short-term memory, so trying to remember… Went to a class at work. I loved it. Decided to become an instructor. It is just that… It's trying to remember, like, 11 routines. I cannot fit anything else in. Can't remember how to do my work. But I've got my little routines. And I forget them. You know. And things like that. But I think it's good for your memory, because everything else I just forget. But that, I've got to try and remember, even if it's just for that one hour. (L1115)
>
> PT8: It probably sounds weird, but my concentration. My memory. Because, the pain – yeah, it's there and you accept it. But the concentration really drives my mad. It's frustrating. The concentration is, to me, the worst… The one that has the worst effect on me.(L627)

Because of the pain severity and the frequent flare-ups, the participants reported that they could not function or preform daily living activities. They also noted how they felt frustrated because their fibromyalgia symptoms were perceived as cognitive dysfunction.

Overall, the emotional impact of FMS could greatly affect the individual living with the condition. Sleep disturbance, memory impairment, depression and anxiety were each discussed by the participants. With respect to clinical practice, the understating of the physiology and pathophysiology of FMS pain and the influence of symptoms by GPs and professionals is required. Healthcare professionals must value the pathophysiological process occurring during a pain experience. The participants believed that HCPs should take part in education programmes to value the pain process and the experience of living with FMS, and to inform the interventions prescribed for the condition. In general, the study revealed enormous variations in the pain experiences, journeys to diagnosis, and views among people with fibromyalgia regarding their condition.

3.6 Fibromyalgia Impact Questionnaire

Regarding the impact of fibromyalgia assessed by use of the FIQ, the total score of the domains can be found in appendix 16. The mean score shows a high impact of fibromyalgia in the participants' sample, as can be seen from Table 3.7.

Table.3 7: Total FIQ score

Participant Number	Total FIQ Score
1	84.25
2	70.82
3	58.38
4	88.68
5	80.53
6	86.1
7	80.67
8	56.67
9	75.67
10	69.1
11	85.53
12	67.1
Average	75.29167

As can be seen from table 3.7 show, the total FIQ scores for all participants are presented, and also the mean score. The average FM patients score about 50, while the severely afflicted score 70 plus. 88.68 represent the highest score recorded in this study, followed by 86.1, 85.53, 80.53, and 80.67, while the lowest score recorded was lowest score 58.38. An average score of 75.29 was recorded, indicating the high scores of those participants, and that their daily living activities are affected by FMS.

3.7 Toronto Alexithymia scale (TAS)

The subjects were asked to indicate the extent to which they agreed or disagreed with each statement on a five-point Likert scale. The statements related to difficulty identifying feelings (DIF), difficulty describing feelings (DDF), and externally-oriented thinking (Baeza-Velasco et al.). The mean score result of TAS shows high alexithymia in this sample of participants, as Table 3.10 shows below.

The participants were asked to rate (i.e. score) 20 TAS items using a Likert scale, ranging from 1= very slight or not at all, 2= a little, 3= moderate, 4=quite a bit, and 5= extremely. The total combined score of all participants was 717. A score equal to or less than 51 indicates non-alexithymia, equal to or greater than 61 indicates alexithymia, and between 52 and 60 indicates possible alexithymia.

Table 3.8: The participants' scores on the "difficulty describing feelings" category

DDF												
	PT1	PT2	PT3	PT4	PT5	PT6	PT7	PT8	PT9	PT10	PT11	PT12
1	1	3	2	2	3	4	1	4	3	1	2	2
3	1	3	3	5	3	5	5	2	5	5	5	4
6	2	3	4	5	4	5	1	3	5	2	4	2
7	1	2	4	4	3	5	2	3	3	5	2	3
9	1	2	4	4	3	5	4	3	5	3	5	4
13	1	5	2	4	3	4	1	1	3	2	1	2
14	1	5	2	5	3	4	1	2	5	2	2	1

Table 3 9: The participants' scores on the "difficulty identifying feeling" category

DIF												
	PT1	PT2	PT3	PT4	PT5	PT6	PT7	PT8	PT9	PT10	PT11	PT12
2	3	5	4	4	4	5	5	4	4	2	3	4
4	4	4	4	5	3	5	3	3	3	2	3	3
11	2	2	3	3	4	4	1	3	1	2	2	1
12	1	2	1	5	3	1	1	1	1	1	2	2
17	1	2	1	4	4	5	1	5	5	1	2	3

Table 3. 10: The participants' scores on the "externally oriented thinking" category

EOT												
	PT1	PT2	PT3	PT4	PT5	PT6	PT7	PT8	PT9	PT10	PT11	PT12
5	3	2	4	1	2	4	3	4	5	4	2	2
8	4	3	3	4	3	4	3	3	5	1	4	4
10	3	1	4	1	2	2	1	4	5	4	2	3
15	4	4	5	1	3	5	3	2	5	1	3	3
16	5	4	2	5	3	3	1	5	3	3	1	4
18	2	2	4	1	2	2	1	3	5	3	5	2
19	5	3	3	5	2	5	5	3	2	3	2	3
20	4	4	1	3	3	4	1	2	1	1	1	5
Total	49	61	60	71	60	81	44	60	74	48	53	56

Total scores of each participants showed that the highest score is 81 score and another participant present the score of 74 participant, participant scored 71, one participant scored 61 followed by three participant has reported the score of 60. As it can be seen in the table (3.10), three participants reported less by 44, 48 and 49. The total score for 12 participants 717 with average of 59.75 see table (3.11)

Table 3. 11: The total scores and the average score of the sample

PTs	1	2	3	4	5	6	7	8	9	10	11	12	Average
Total scores	49	61	60	71	60	81	44	60	74	48	53	56	59.75

3.8 summary of key findings

- The primary qualitative study highlighted some difficulties that the participants faced regarding a perceived lack of understanding by healthcare professionals and the general public concerning the management of their condition, and the emotional and physical impact of FM.
- This lack of understanding often led the participants to avoid going back for further medical interventions. These findings suggest that the participants were not managing their daily living activities, due to symptoms such as disabling fatigue and worsening pain. The study also highlighted the variety of intervention approaches used, with varying and often limited success.
- Emotional impact features (fatigue, depression and anxiety) were found to accelerate the participants' pain, and affect their daily living activities.
- Participants had high FIQ scores indicating they were severely affected by the impact of fibromyalgia and also had high alexithymia scores.

3.9 Discussion

This study has expanded the knowledge base regarding people views, experience of living with chronic widespread pain (FMS) and understanding of issues with coping and self-management of FMS. A number of studies (Macfarlane et al., 2016, Wolfe et al., 2011, Fitzcharles et al., 2013d), suggested that initial management should involve patient education and focus on non- pharmacological therapies and a specific need for individuals by shared decision-making with patients and may involve psychological therapies with pharmacotherapy for pain or a multimodal rehabilitation programme for more severe disability. The current study developed these findings by additionally

using FIQ self-report and TAS instrument to explore FM impact, patients' ability of self-managing and the impact of psychological and emotional features that impact upon fibromyalgia patients' daily living. The results are broadly consistent with a Belgian study by Calsius (2015) . This qualitative study collected data in a focus group of 30 women diagnosed with FM ,used two self-report questionnaires (Toronto Alexithymia Scale TAS -20 and Hospital Anxiety and Depression Scale HADS),. recruited from physical therapist practices. Alexithymic FM patients, were found to be primarily failing in expressing their bodily experiences a representation of alexithymia. The current study has developed an in depth understanding of the experience of living with FMS and views and experiences of healthcare and interventions within a UK setting.

The aim of this study was to capture service users' views and experiences of fibromyalgia. This study addressed six key questions: -

- To explore the experience of the process of obtaining a diagnosis .
- To explore the emotional experiences of sufferers.
- To explore the experiences of support.
- To explore the experiences of coping and managing daily living activities
- To explore the interventions that have been accessed by sufferers and their experiences of these interventions.
- To explore the description of living with pain.

This qualitative study highlighted four main themes, journey of diagnosis, coping with variability and unpredictability of symptoms, availability and satisfaction with current health care practices and services and the emotional influences. Participants reported facing difficulties regarding a perceived lack of understanding by health and medical professionals and community regarding management of the condition and the emotional and physical impact of FMS. This lack of understanding often led participants to avoid going back for further health and medical intervention. These findings suggested people were not managing daily living activities due to symptoms such as disabling fatigue and worsening pain. This part of the study has illustrated a variety of intervention approaches are used with variable and often limited success. The participants' perspectives have illuminated the need for support required for people living with FMS and need for education and standardisation of approaches in clinical practice. These findings have similarities with a qualitative study by Briones-

Vozmediano et al. (2013) who conducted a study in Spain of fibromyalgia patients (n =12), 10 were women and 3 were men aged range 29 to 61 years. Patients recruited were from associations in a region in the east of Spain, utilising semi -structured interviews to understand the experiences of challenging FMS cases. Patients reported that the need for greater moral support from professional was required. Participants also reported symptoms characteristic of flares included pain, fatigue, body aches/exhaustion, and variety of other symptoms. This study shares some similarities with the current study, however the therapeutic relationship with healthcare professionals was commented upon positively. The finding of the need for support was illuminated in the current study. Briones-Vozmediano et al (2013) was undertaken in Spain, thus the study undertaken as part of this thesis has provided understanding of support required within a UK setting. It is thus clear, that individuals living with FMS feel the need for further support from healthcare professionals.

A recent USA-based qualitative study by Vincent et al. (2016) of 44 participants demonstrated that periods of symptom exacerbation (flares) are commonly experienced by patients with fibromyalgia, and that symptoms of flares can be differentiated from every day or typical symptoms of fibromyalgia. These observations concur with our findings, where the participants reported symptoms characteristic of flares, including body aches/exhaustion, pain, fatigue, and a variety of other symptoms. In addition, our study showed that the participants sought more support from GPs and health professionals for cases of flare-ups, as they could not cope with the pain. The current study described the views of living with pain, and how emotional factors impact patients' symptoms and daily living. It used framework analysis to analyse the text, allowing for an in-depth exploration of the findings. In contrast, the USA study used content analysis, which may have resulted in a lack of in-depth analysis and discussions.

The findings from our study also share some similarities with the qualitative study of (Eilertsen et al., 2015), which explored the similarities and differences in the experiences of fatigue in FMS compared with multiple sclerosis and ankylosing spondylosis. The study reported that FMS patients described a feeling of invisibility and a difficulty describing the experiences of fatigue. In our study, this aspect was clearly observed, as the participants described the influence of fatigue in a lot of detail, including the impact of unrefreshing sleep and fatigue on emotions and daily life. As

such, the study was able to elucidate the links between pain severity and sleep difficulty and fatigue.

A qualitative study by Dennis et al. (2013) of women with FMS (n=20) ,were contacted through an online support group and a 'real world' support group. Participants demonstrated that symptoms of fibromyalgia acted as parallel effects of a comorbid illness. The study pointed out that patients should be informed that medications' effects will take time, and that a rapid reduction of pain is not predicted in most cases. Furthermore, GPs and healthcare professionals in both primary and secondary care sites need to consider a holistic approach to diagnose and treat chronic widespread pain and comorbid conditions that addresses both the physical, psychosocial and emotional impact and processing. Moreover, the psychological issues aggravated the patients' symptoms and pain intensity were reported.

In our research study, the participants reported a lack of energy and being unable to function, as the fatigue interfered with their daily activities, and made them feel tired for most of the day. In addition, the participants discussed how the fatigue and chronic widespread pain associated with their condition often influenced all aspects of physical activity.

A narrative interview by Sallinen et al. (2010), focusing on the experience of work ability and functioning of patients livening with FMS (n=20) of women aged 34–65 years was conducted, patients participated in FM rehabilitation courses at the Rheumatism Foundation Hospital. The study identified four concerns regarding lived experience, coping with fluctuation symptoms, exhaustion confusion, and severe pain and fatigue combined with substantial decrease in work ability and functioning a dynamic movement. However, people with chronic widespread pain are often concerned about unemployment and having high medical utilizations rates regard to fatigue symptoms and was not been relieved by rest. Furthermore, our study has reported the effect of fatigue and pain among fibromyalgia patients in the UK, and discussed the emotional impact of the symptoms on patients' lives.

Another qualitative observational study by Lukkahatai et al. (2016) used a sample of 120 women diagnosed with FM recruited from community physicians and practitioners, and utilised a self-report questionnaire to measure fatigue and pain, and a cluster analysis to analysis the data using SPSS. The non-UK study found that fatigue

was associated with widespread pain, symptoms flare-ups, cognitive dysfunction and psychological aspects such as anxiety and depression. The limitation of the study that attempted to identify relationships among self-reported symptoms. It is commonly known that the intensities of FMS symptoms change frequently. In contrast, our qualitative study developed an in-depth understanding of the issues associated with fatigue in FMS, and the links between pain and the wider impact on the daily lives of patients, which could not have been achieved through a self-report questionnaire.

A study by Eilertsen et al. (2015) found similar findings to those of our study regarding the unpredictable and uncontrollable aspects of fatigue. In particular, the impact of tiredness and fatigue, resulting from nonrestorative sleep, on daily functioning was discussed. The invisibility of fatigue was highlighted as a challenge, which was also discussed in-depth our study. Similar to our findings, the lack of understanding and belief were reported in this study, where the participants pointed out that clinical awareness may allow healthcare professionals to offer adequate information on FMS, and establish effective intervention approaches for managing the condition.

The difficulties facing FMS patients regarding sleep disruption, physical functioning and disability, tiredness, and psychological hardships such as depression and anxiety, have been highlighted by a number of research studies. A qualitative cross-sectional study conducted in Spain by Miro et al. (2011) used semi-structured interviews of women with FMS (n=104) recruited from community. The study highlighted an eloquent point that sleep disorders mediate pain and emotional distress, and that sleep quality plays a significant role in the relationship between pain and functioning. Our study also provided an insight and a deeper understanding of FMS patients' experiences of sleep disorders during the day, where the participants reported feeling useless, finding it difficult to perform any daily activity, and waking up unrefreshed and exhausted, even after having had sleeping tablets'

Non-pharmacological approaches of coping with pain should be debated, including the importance of approaches that target anxiety and sleep disorders. Access to physiotherapy and psychotherapy needs to be recommended, or at least given more consideration for FMS patients. These procedures and practices do not appear to be currently in place based on the findings of our study.

A narrative review by McMahon et al. (2012),focused on the theories and narrative of chronic illness experience, and examined the impact of chronic widespread pain conditions on the identities of patients. The review aimed to empower people to tell their own personal experiences of the diagnosis process and impact of fibromyalgia, and used narrative analysis to review the illness experiences from narrative studies on chronic pain. In contrast, our study used a framework analysis to provide an in-depth account of the experiences of misdiagnosis, and the lack of understanding of the pain that FMS patients suffered, and how they coped with such pain. Furthermore, the use of framework analysis enabled the provision of in-depth information on the complexity of the living experience with such pain, and emotional influences of the condition. Our study reported that there was poor knowledge and a lack of understanding of the etiology and pathogenesis of FMS by physicians and HCPs, which made the participants feel disappointed and frustrated about the social and community consequences.

A qualitative study by Jelin et al. (2012) focused on the provision of intervention approaches using web based technology (web-based home interventions) in Norway. Seven women who were interviewed about their experiences of such interventions programmes, telephone interviews were chosen which utilised information technology, such internet and smart phones, to facilitate communications between healthcare providers and patients. The data was analysed by systematic text consecrations, and the results highlighted the formation of relationships of trust between HCPs and the patients. In addition, HCPs were found to play an important role regarding the assessment and management of chronic pain, updating knowledge, and working together with the patients to deliver batter services. The study also highlighted the difficulties HCPs faced due to the limited availability of resources, research and financial support. The participants valued HCPs' support and were able to build a rapport with them, extending beyond dealing with their condition. In addition, the participants believed that the availability of nurse care might assist the consultation to and support of people with chronic pain. Furthermore, they also mentioned that the use of technology could help to provide patients with an easy communication connection to healthcare professionals and nurses, and facilitate the access to high quality care when they need it.

A review study of 75 articles conducted in New Zealand by Annemarie (2010) emphasised that the crucial distinction between disorder and illness in debating the condition's labels enable access to the health services. The study also stated that the limited currency that fibromyalgia holds in the health dialogue, and the lack of convincing elements of the condition (like clear biomedical indicators that make the condition objectively visible) lead to reduced credibility. However, most of the studies on this context were non-UK based.. Our study depicts the challenges that the participants faced in obtaining a diagnosis, often resorting to seeing multiple healthcare professionals, and feeling a general lack of understanding of their condition. This has important implications for UK based healthcare, in that it highlights that individuals living with FMS are having difficulties with diagnosis and access to relevant services.

A an interpretive study in Sweden discussed the challenges FMS patients faced regarding daily living activities (Audulv et al., 2012). Individuals with the chronic illness (n=21), Eight women diagnosed with FM were interviewed, the participants chosen the location for their individual interviews (e.g., their home, work place, or the university). And although the study's findings had similarities with our study, the focus was to provide a standard to help healthcare professionals support the self-management of patients with chronic pain. However, self-management is often a variable process in chronic disorders in general, and in fibromyalgia specifically a (musculoskeletal pain disorder), as the illness and life circumstances are ever-changing, which might demand continuous changes and adaptations to the individual's life. Due to these reasons, the empirical qualitative study reported in this thesis aimed to capture the day to day lives of individuals, the impact of fibromyalgia, and the challenges associated with pain and fatigue.

The findings of our study corroborate those of the study by Cooper and Gilbert (2016) in which 15 participants living with fibromyalgia were interviewed in South Africa about their social support experiences (Cooper and Gilbert, 2016). The study highlighted the importance of social support for coping with the illness experience of fibromyalgia, due to the complex nature of the condition, and the uncertainty and multiplicity of its features. The limited access to the healthcare system was also discussed, as the participants reported the lack of support they received regarding the management of their condition. Our study also showed that the availability of services

was a concern, and demonstrated several shortcomings in the referral process. In addition, the participants believed that the lack of support had an enormous influence on their daily lives.

Self-management of pain was also frequently discussed by participants. Self-management is complex and involves managing the physical and psychological aspects of chronic pain conditions (Stewart et al., 2014). The previous study analysed n=45 studiesof the experiences of FMS symptoms using thematic analysis, and identified numerous physical, psychological, and social health consequences due to chronic pain or long-term pain. Likewise chronic widespread pain classified as musculoskeletal chronic pain represents the majority of pain disorders affecting older adults. During the interviews, the psychological impact of the condition was also frequently discussed, where the participants mentioned a lack of understanding from healthcare professionals of their psychological needs. As such, support with the physical and psychological aspects of the condition must be provided, current challenges and shortcomings in this regard must be addressed. Furthermore, the in-depth discussions on the emotional impact of fibromyalgia in the interviews demonstrates the need to focus on this aspect within interventions, and to educate healthcare professionals on its importance, in order to effectively support the self-management of the condition. This contrasted with another study by Toussaint et al (2014) of 30 women living with FMS aged 40 - 54 years, who were assessed during forgiveness education sessions and analysis of themes. The study were conducted on Mayo Clinic, Rochester, USA using a qualitative assessment of a forgiveness education for these patients. The study findings suggested that forgiveness education is acceptable and feasible in patients with fibromyalgia.

A qualitative study by Matthias et al. (2012) .discussed the challenges associated with service availability issues with participants living with chronic pain (n=26), female patients recruited from a veterans primary care clinic in Indiana, USA. Self-management, education and the important role played by nurse care were all discussed by the participants. The study highlighted varying perceptions of nurse care, with most participants viewing nurses as good listeners and a strong source of support. In addition, the participants mentioned how nurse care helped them overcome frustrations and lack of motivation, and provided them with emotional support. The study used grounded theory analysis, which focuses on understanding participants' perspectives.

Although the study's findings had some similarities with our study, the availability of nurse care was not frequently discussed in our study, unlike rheumatologists and GPs, who were frequently mentioned. This may be explained by the different contexts and samples of the two studies, where in our study, the participants were concerned about a direct line of support from nurses (help in between), as they felt frustrated with the limited access to the healthcare system when they needed it.

Several previous studies have focused on the development of clinical guidelines for the diagnosis and management of fibromyalgia. However, there is limited literature exploring the actual illness experience (Raff et al., 2014, Namane et al., 2013, Govender et al., 2011). The qualitative study reported in this thesis aimed to capture the service users' views and experiences of fibromyalgia and fatigue symptoms to provide an in-depth understanding of the condition, and discuss the services specifically offered for chronic widespread pain. The qualitative findings gained from the participants' experiences showed a lack of knowledge among healthcare professionals and communities about the condition.

The psychosocial impact of FMS on patients, which includes emotional distress and emotional awareness, expression and processing (alexithymia), seems to play a key role in the management of the condition. However, there is an unclear association between alexithymia and pain intensity, as has been highlighted in some studies, where alexithymia appeared to be mediated by negative effects such as depression. (Lumley et al., 2011, Di Tella and Castelli, 2013, Calsius et al., 2015, Di Tella and Castelli, 2016). Our study showed that depression was reported by patients living with FMS, who felt that the unpredictability of symptoms and their flare-ups made, it a struggle for them to function and control their lives. Participants who reported being depressed tended to report pain severity and feeling frustrated.

A previous study by Tuzer et al. (2011) of 70 fibromyalgia (FM) patients using the Toronto Alexithymia Scale, reported difficulty in recognising physical sensations by patients, as the bodily expressions of emotions could lead alexithymic individuals to misunderstand their emotional arousals as signs of syndrome, further worsening the symptoms. Our qualitative study focused on the experiences of living with pain, where the participants reported difficulty in describing and understanding the symptoms. A

difficulty in identifying feelings can predict affective pain, as well as psychological aspects, particularly anxiety.

The findings of our study have parallel values with a previous qualitative study by Arnold et al (2008) in which 48 women diagnosed with FMS. focus groups were conducted at each of three sites including, Seattle Rheumatology Associates (community-based rheumatology private practice), Seattle, Washington, University of Cincinnati Medical Center (university-based primary care private practice), Cincinnati, Ohio and University of Michigan Medical Center (university-based rheumatology practice), Ann Arbor, Michigan. Patients reported that had the greatest impact on their quality of life including pain, sleep disturbance, fatigue, depression, anxiety, and cognitive impairment. They had a substantial negative impact on social and occupational function. Likewise, participants in our study determined that pain and fatigue were the most of clinical features of FMS.

Contrary to our study participants were mostly resembled the difficulty to copy with pain. A qualitative study by De Vries et al (2011) semi-structured interview was conducted among 21 subjects (9 male, 12 female)diagnosed with chronic musculoskeletal pain (CMP) . Data was analysed by means of thematic analysis. Participants reported a variety of styles in coping with pain including some promoting and the effect of pain medication varied, finding access to healthcare services, and asking for support were considered.

The finding of our study showed similarity to study by Rodham et al (2010) conducted structured interviews with four women with FMS, participants recruited through the local FMS support group in the south-west of England, Data were analysed using interpretative phenomenological analysis. Participants reported feeling isolated from healthcare professionals, whom they felt they had to convince that they had something ‘real’ and from friends and family because the unpredictability of their symptoms.

3.10 Conclusion

The study presented in this chapter discussed the difficulties that the participants faced regarding a perceived lack of understanding by healthcare professionals and the general public of the management of FMS, and the emotional and physical impact of the condition. This lack of understanding often led participants to avoid going back for further health and medical interventions. These findings show that the participants

were not able to manage their daily living activities due to symptoms such as disabling fatigue and worsening pain. The study also highlighted that a variety of intervention approaches were used with varying and often limited success. The participants' perspectives have illuminated the need for support required for people living with FM and need for education and standardisation of approaches in clinical practice. To date there are cross sectional studies focusing on Alexithymia, In addition, our qualitative study has provided depth to the existing cross sectional studies focusing on alexithymia, through the frequent reporting of cognitive dysfunction and distress

Seeking support from a health and medical professionals featured strongly throughout the interviews. Thus, their role in supporting management of FMS is prominently highlighted, the subsequent phase of the current research is a quantitative study based on a national survey of healthcare professionals. The study aims to describe current FMS practice in the UK, analyse the differences in approaches for the management of FMS between healthcare professionals, and explore attitudes and opinions regarding the outcome of interventions. The study aspires to contribute towards decreasing the integrated nature of pain and the impact of the condition on daily life, as well as to support people living with FMS to understand their condition, and to ultimately self-manage.

CHAPTER FOUR

A Survey Exploring the Assessment, Management and Interventional Approaches to Fibromyalgia

4.1 Introduction

4.1.1 Section A: United Kingdom Fibromyalgia Survey

In a previous study upon which our study was based, a self- completion questionnaire was used to survey two professional interest groups in rheumatology recruited from the National Association of Rheumatology Occupational Therapists (n=140), and the Rheumatic Care Association of Chartered Physiotherapists (n=61). The foremost therapeutic objective targeted by occupational therapists (OTs) was increased functional ability, while increased exercise tolerance and general fitness was the main aim of physiotherapists (PTs). Pain reduction and management was rated as the second objective for both groups (Sim and Adams, 2003b). Larger scale studies have since been conducted and are presented below.

In a descriptive survey of Latin American and European patients (n=900, aged: 45–59 years), and physicians (n= 1824) who had been in practice for 11–30 years across regions, it was found that patient- and physician-rated disease perception and impact were often higher in Latin America than in Europe. Patient and physician perspectives concerning FMS impact and disruption were often misaligned within the same region, when incorporating cultural differences. As with all surveys, some limitations were present, including that respondents may have not perfectly recalled their experiences and feelings at the time of the survey, as respondents' feelings, attitudes, and perceptions are subject to change with time. In addition, the survey only provided a snapshot of the respondents' experiences, and did not seek to address how these might have changed longitudinally (Clark et al., 2013).

A cross-sectional survey of FMS patients (n=1651) was used to validate the fibromyalgia survey questionnaire (FSQ), instruments also, including the wide pain index (WPI) and the Symptoms Severity Score (SSS). The participants, who all had a diagnosis of FMS, were recruited by FMS self-help organisations and nine clinical institutions of different levels of care. The participants were assessed using the American College of Rheumatology's 1990 classification criteria, and the data analysis was descriptive. The study demonstrated the feasibility, reliability and validity of the FSQ in a survey of German FMS-patients. While the reliability, and convergent and discriminant validities of the FSQ were good, further validation studies of the FSQ in clinical and large population settings are needed. The study confirmed

the high levels of distress reported by FMS patients, which can be located at the extreme end of the continuum of distress, and the conceptuality of FMS as a varying illness (Hauser et al., 2012a).

A large scale survey in six European countries was conducted by Perrot et al. (2012) on 1622 participants, of which n=809 were primary care physicians (PCPs), and the remainder being recruited from secondary care, which included rheumatologists, neurologists, psychiatrists and pain specialists. Data was analysed using descriptive and inferential analysis, and it was found that almost 90% of PCPs reported difficulty in discriminating FMS symptoms from other comorbid conditions, a percentage that was significantly higher than in the other specialties. The study highlighted the need for improved training of physicians, particularly PCPs and psychiatrists, in the diagnosis of FMS. The questions in this survey were framed in "yes/no" or 5-point Likert scale formats, which did not capture detailed accounts of physicians' experiences, or additional unanticipated responses (Perrot et al., 2012).

In a Japanese market research, an internet survey of 20407 participants was conducted (Nakamura. et al., 2014). The Japanese Fibromyalgia Impact Questionnaire was used to determine the epidemiologic features and symptoms of FMS, and compare them to other chronic pain disorders. Statistical analyses were performed using the SAS software and an analysis of covariance. The study found that individuals with FMS had greater restrictions on their functionality than individuals with chronic pain . There were several limitations to the study, including the fact that people with no or limited internet access, and people who were not included in the database, could not participate in the survey. Moreover, no physicians assessed whether the participants met the diagnostic criteria for FMS in this survey.

Although there is literature regarding fibromyalgia in Europe, USA and Latin America, there has been relatively little attention to the condition in the Middle East, particularly in such countries as Libya, where pain management is not a high priority of healthcare system. Furthermore, the availability of opioid medication is limited, and pain-related governmental policies are absent (Elzahaf et al., 2016). Patients are often diagnosed with chronic pain rather than receiving a specific diagnosis of fibromyalgia. In addition, there are few studies that have been conducted on FMS. A cross-sectional telephone survey was conducted using an Arabic version of the Structured Telephone

Interviews Questionnaire on Chronic Pain. Twelve individuals were interviewed, and it was found that the prevalence of chronic pain lasting for longer than 3 months in the general adult population of Libya was approximately 20%, which is a comparable level with those of Europe and North America.

The most commonly reported causes of chronic pain were disc problems, headaches and migraines. Furthermore, the most common sites of pain reported by the respondents were the upper, lower back (24.6%) and knees (13.1%). In a study by (Tashani et al., 2017) conducted on 71 patients, 34% were diagnosed with having low back pain, 19% with osteoarthritis and rheumatoid arthritis, and the rest of patients had multiple sources of pain, including neck and shoulder pain, and lower leg and foot pain. The study used a cross-culturally adapted PASS20 questionnaire to measure pain related anxiety. The finding of this study suggest that Libyan patients with chronic pain exhibited high levels of fear of pain and impaired concentration. However, several limitations were reported which might restrict the validity of the findings, including the small sample size, and the fact that the treatment received by the patients was not documented. Furthermore, it was not possible to evaluate the construct validity of the Arabic pass20 because the study did not administrate other instruments that assess pain related anxiety symptoms.

The aforementioned studies suggest that health policies, and education and training programmes in Libya need to be improved to ensure that patients with chronic pain receive effective management (Elzahaf et al., 2016). Due to the paucity of literature in the Middle East on FMS, our study aimed to conduct a preliminary survey of current practice regarding the identification, diagnosis and management of chronic widespread pain, and establish whether clinicians would consider that there were patient cases corresponding with the definition of ‘fibromyalgia’ provided by the ACR.

Thus, this exploratory survey study aimed to describe and compare the current practice in the UK and Libya regarding the assessment and management of fibromyalgia, and the attitudes and opinions regarding the condition.

4.2 Aims

- To explore the current practice for FMS in the UK and Libya
- To consider similarities and differences in views and approaches to the management of FMS between the UK and Libya
- To explore the attitudes and opinions regarding the outcome of interventions

4.3 Pilot study

The nature of this study was explorative, and the questions of the quantitative survey were based on the previous study by Sim and Adams (2003). The survey was checked for validity and consistency by an academic physiotherapist, and then piloted on the six members of physiotherapy association of the UK. The responses obtained from the pilot study anticipated that the response rate of the questionnaire was likely to be 50%. However, due to the lower rank devoted to participating, a response rate of approximately 20% was expected. Amendments were made to the questionnaire based on the feedback from the pilot study, which included terms and questions relating to interventions approaches. It is generally recommended to conduct a pilot study on a smaller sample (usually about 10% of the final sample) to help adapt the final study based on the anticipated response rate (Mathers, 2009).

4.4 Methods

4.4.1 Design of the questionnaire

This exploratory study was conducted in order to collect data on a wide range of topics relating to the practice of fibromyalgia assessment and interventions. A survey was used in order to obtain a large sample size and address a broad range of relevant topics. The questionnaire was designed specifically for the study, and developed based on an earlier work by (Sim and Adams, 2003). The questions were mostly 'closed', and were either categorical or used ordinal Likert scales. The questionnaire consisted of 23 questions, and contained some open questions and spaces for comments.

The demographic data included region, profession, speciality, current professional status, patients' descriptions, and the proportion of patients diagnosed and referred who fulfilled a case definition of fibromyalgia. The questionnaire enquired about the

practice of healthcare professionals regarding the diagnosis, assessment and management of FMS.

In this study, in order to establish a case definition for the purpose of the survey, we included a definition of FMS in the questionnaire. This definition was based on that of (Wolfe et al., 1990), and the American College of Rheumatology's 2010 classification criteria (Giordano et al., 1999). We anticipated that healthcare professionals would have treated patients with FMS who had been referred under a variety of diagnostic labels.

4.4.2 Ethical approval

The study's protocol was submitted on the 9th of September 2014 to the Departmental University Research Ethics Committee, who requested major amendments before an approval could be granted. The resubmission of the ethics application was made on the 3rd of March 2015. The project then received an ethical approval through the Department of Sport, Exercise and Rehabilitation's ethics committee on the 12th of May 2015, with reference number HLSSA300415 (see the Appendix (3).

4.4.3 Participants

The participants included listed members of the British Pain Society (BPS), which represents healthcare professionals in all regions of UK. The participants were identified from the BPS' database as professionals who were interested in the area covered by the survey, in order obtain a representative sample of UK HCPs. Initial

contact was made with the pain society to provide a database of healthcare professionals.

The sample of participants also included a representation of healthcare professionals from Libya. The setting for survey B was Tripoli (the capital city) and its neighbouring city, Zawia. These participants were selected to identify and explore the existing Libyan HCPs' practices and attitudes on FMS. The participants were recruited by principal researcher, who had personal connections with HCPs in Libya, via email or face to face meetings. The sample of Libyan healthcare professionals included physicians, physiotherapist and rheumatologists. A questionnaire with an invitation, consent form and information sheet was provided to the participants. All personal

information was anonymised for the purpose of the research, and it was indicated that feedback would be sent to the participants upon their request. The sampling strategies and criteria used for recruiting participants to this study depended on the population of interest, the features and patterns of the condition under study, and the context in which interventions and services were provided.

Effective sampling, which determines how well a sample represents the population, before drawing the information required (Curtis, 2013). The researcher should be aware of the limitations of the sampling frame, and attempt to address them in order to enhance the external validity of the questionnaire, and contrast it with the internal validity, when considering the generalizability of the study's results.

The survey was distributed to the healthcare professionals (n=600) identified and recruited from the British Pain Society's database. The questionnaire queried the participants regarding their beliefs and current practices, as well as their views and attitudes concerning the assessment and management of musculoskeletal widespread pain. The respondents consisted of 53 UK-based healthcare professionals, two of whom were not UK residents, who completed the questionnaire and returned it to the address provided in a paid envelope. The same questionnaire was sent to Libyan healthcare professionals, where the respondents (n=15) included physicians (n=8), physiotherapists (n=6), and a rheumatologist (n=1). This sample was recruited through direct personal communication by principal researcher, who had personal links with healthcare professionals in Libya. In addition, the sample recruitment did not require ethical approval, according to the Libyan health guidelines.

4.4.4 Sample recruitment

The potential participants were identified by the British Pain Society, who agreed to make their database of members available to us. Potential respondents were thus identified, representing a range of UK health professionals who were interested in pain management.

An invitation letter (Appendix (12)), a written explanation of the survey (information sheet) (Appendix (14)), and a consent form (Appendix (13)) were combined with the questionnaire (Appendix (15)). An attached reply slip (a stamped addressed envelope) was also included.

4.4.5 Design of the survey

The survey was designed based on a previously published questionnaire-based survey study in the UK (Sim and Adams, 2003). The current questionnaire aimed to describe current UK healthcare practice regarding the assessment and management of fibromyalgia. The diagnostic criteria were provided and illustrated in the adopted version of survey used a diagram according to the ACR criteria (2010).

The principal components of the survey were similar to those of a previously published survey of OTs and PTs (Sim and Adams, 2003b), Sim and Adams, 2003), where our version was modified to enhance the aforementioned previous work, and include multidisciplinary teams within the UK. Closed and open questions were used, with some open questions being used to gain an understanding of issues in more detail and depth (Plowright, 2011).

The content of the questionnaire was based on a review of the literature on FMS, including the small amount of literature available on the physical management of the condition.

The principal components of the survey were:

- Demographic information
- Occupation and area of work
- Diagnosis, frequency and source of referrals
- Usual management objectives
- Specific interventions adopted
- Perceived responsiveness of patients to physical management
- Attitudes and beliefs regarding the nature of FMS and its management

Most of the quantitative data was gathered in the form of frequency counts and median values.

4.4.6 Data collection procedure

The participants identified through the membership database of the BPS received an invitation letter asking if they would participate in this research. They also received an information sheet explaining the research, and an informed consent form. A reply slip and a pre-paid envelop were also sent to the participants, so they could indicate their

agreement to participate in the study. The questionnaires were returned by post to the researcher. A second mailing was carried out three weeks after the initial mailing.

4.4.7 Validity and reliability

Content and face the validity was assessed and evaluated by n=4 Health Care Professionals HCPs. Amendments were made in light of pilot study and their comments. All participants received the same questionnaire

4.5 Data Analysis

Appropriate descriptive and non-parametric statistics using SPSS version 24 were carried out. Most data was presented in the form of frequency counts and median values. Comparisons were made between the UK and Libya on the attitudes and opinions regarding fibromyalgia. Statistical significance was set at p=0.05, and all tests were two-tailed.

4.6 Results

This section presents the results of the questions on the general details of the respondents and their practices. Descriptive analyses were performed on all data to

describe clinicians' practices and views. The participants were also able to make some comments if they wished to do so.

4.6.1 Number of respondents

The respondents consisted of 53 members of the British pain society (BPS), initial sample

size, were 600 members of the (BPS), making the total sample size n=53. The data on the initial questionnaires sample size (i.e. the number of potential participants identified and invited), and number of UK respondents is presented in Table 4.1

Table 4 1: Response rate

Initial sample size	Number of UK respondents
600	53

4.6.2 Demographic data

Table 4.2 shows that the greatest number of UK responses came from the South East, followed by the Midlands and the South West. This data is also illustrated in Figure 4.1.

Table 4. 2: Analysis of respondents by region

Region					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	North East	3	5.7	5.7	5.7
	North West	2	3.8	3.8	9.4
	South East	14	26.4	26.4	35.8
	South West	8	15.1	15.1	50.9
	Midlands	9	17.0	17.0	67.9
	London	6	11.3	11.3	79.2
	Wales	2	3.8	3.8	83.0
	Scotland	6	11.3	11.3	94.3
	Northern Ireland	1	1.9	1.9	96.2
	Non UK	2	3.8	3.8	100.0
	Total	53	100.0	100.0	

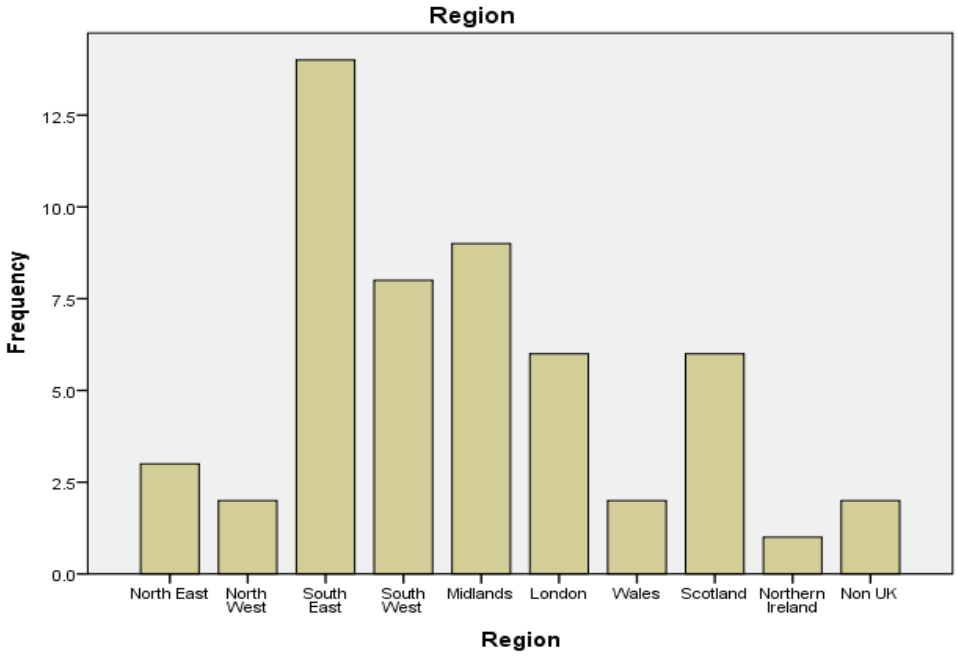

Figure 4. 1: Analysis of respondents by region

Table 4.3 and Figure 4.2 show the division of respondents by profession. It can be seen from the table that most respondents were pain management specialists, followed by physiotherapists. Of the total number of respondents (n= 53), 41 were pain management specialists, four were psychologists, and four were physiotherapists. Other respondents included an anaesthesiologist (n=1), a nurse (n=1), a pain nurse (n=1), and an expert patient (n=1),

Table 4.3: Professional specialties of respondents

Profession					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Pain management specialist	41	77.4	77.4	77.4
	Physiotherapist	4	7.5	7.5	84.9
	Psychologist	4	7.5	7.5	92.5
	Others	4	7.5	7.5	100.0
	Total	53	100.0	100.0	

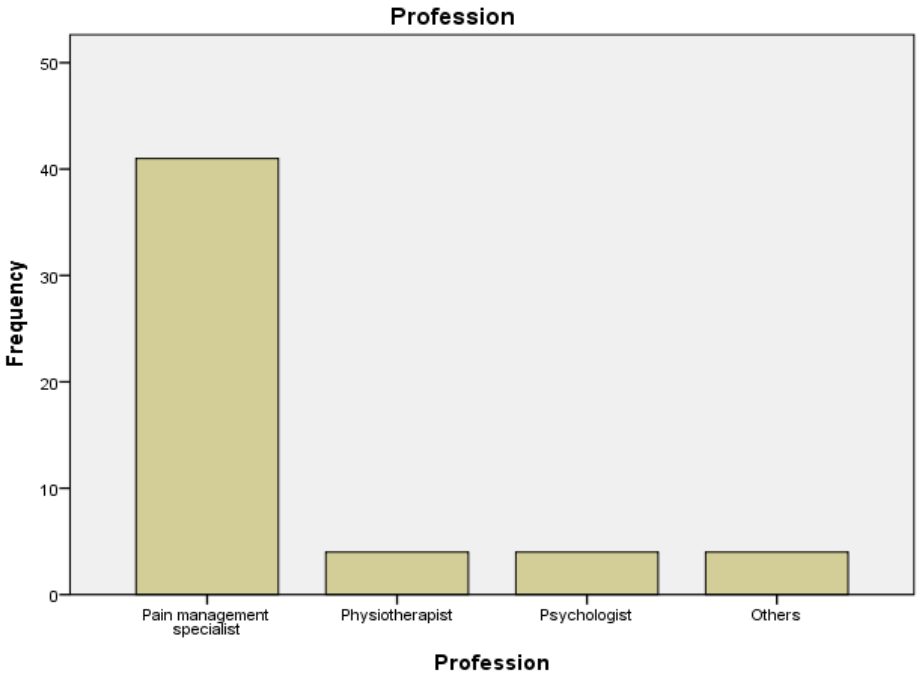

Figure 4. 2: Division of respondents according to their professional specialty

The respondents were asked about the setting in which they worked. There responses showed that that the majority worked in an outpatient setting, as can be seen from Table 4.4. This clinical setting data is also illustrated in Figure 4.3.

Table 4. 4: Clinical settings in which the respondents worked

Clinical Setting					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	In- patients	8	15.1	15.1	15.1
	Out patients	42	79.2	79.2	94.3
	Community	3	5.7	5.7	100.0
	Total	53	100.0	100.0	

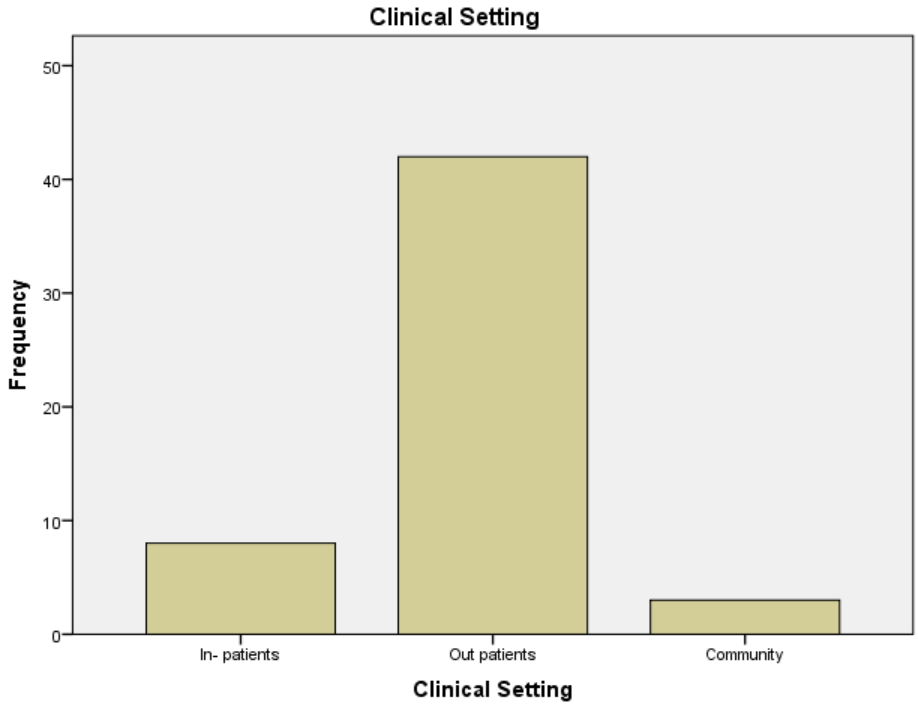

Figure 4. 3: Clinical settings in which the respondents worked

4.6.3 Diagnosis

The respondents were asked if they saw patients that would fit the description of fibromyalgia provided (irrespective of the actual diagnosis), during the last 12 months. The responses show that the majority of respondents saw patients who either closely,

or more or less fitted the description of fibromyalgia (~94%), as can be seen from Table 4.5 and Figure 4.4.

Table 4.5: Proportion of patients fitting the description of fibromyalgia

Patients fit the description in the last 12 months					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes, I have seen patients who closely fit this description	48	90.6	90.6	90.6
	Yes, I have seen patients/clients who more or less	2	3.8	3.8	94.3
	NO, I have not seen patient	3	5.7	5.7	100.0
	Total	53	100.0	100.0	

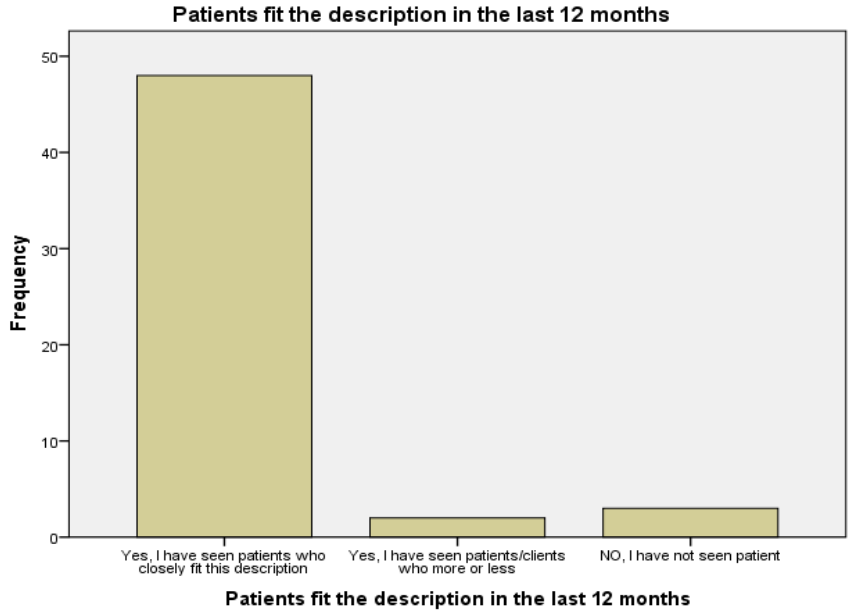

Figure 4. 4: Proportion of patients fitting the description of fibromyalgia.

The respondents were also asked about the number of new patients/clients fitting the description of fibromyalgia seen in the last 12 months. The answers to this questions are presented in Table 4.6, and illustrated in Figure 4.5.

Table 4.6: Number of new patients fitting the description of fibromyalgia in last 12 months

New patients/clients fitting this description in the last 12 months					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1-4 patients, per month.	17	32.1	34.0	34.0
	5-9 patients, per month.	18	34.0	36.0	70.0
	10-15 patients, per month.	15	28.3	30.0	100.0
	Total	50	94.3	100.0	
Missing		3	5.7		
Total		53	100.0		

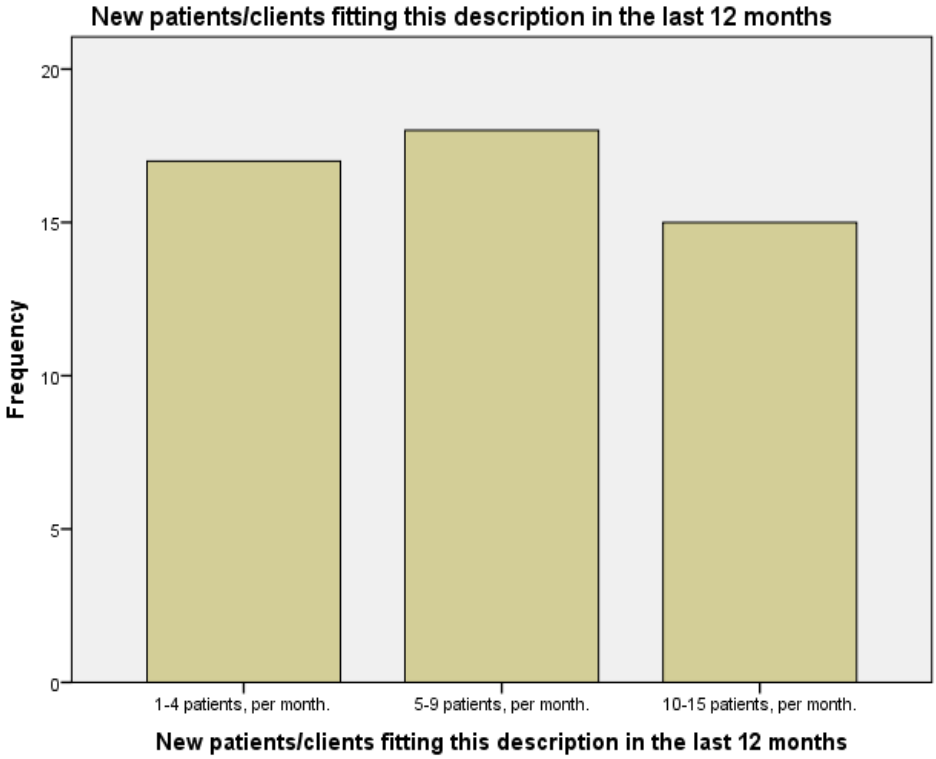

Figure 4. 5: Number of new patients fitting the description of fibromyalgia in last 12 months

Table 4.7 and Figure 4.6 show the proportion of the patients having a diagnosis of fibromyalgia, according to the respondents' answers.

Table 4. 7: Proportion of patients having a diagnosis of fibromyalgia

Proportion of patients having a diagnosis of FMS					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	All of them	2	3.8	4.1	4.1
	More than half of them	24	45.3	49.0	53.1
	About half of them	15	28.3	30.6	83.7
	Less than half of them	6	11.3	12.2	95.9
	Almost none of them	2	3.8	4.1	100.0
	Total	49	92.5	100.0	
Missing		4	7.5		
Total		53	100.0		

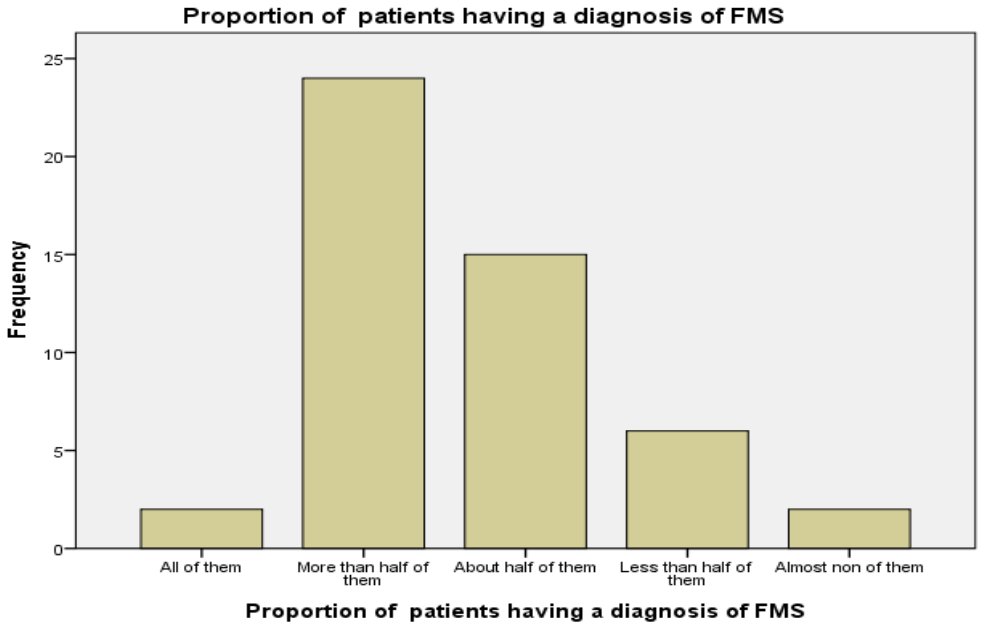

Figure 4. 6: Proportion of patients having a diagnosis of fibromyalgia

The questionnaire also asked the respondents regarding the frequency with which patients fitting the definition of fibromyalgia were referred from specific healthcare sources. The respondents answered using a Likert scale, where 1= often, 2=sometimes, 3= seldom and 4 =never. Table 4.8 demonstrates that the highest median response (of 1) was for general practitioners and rheumatologists, followed by rehabilitation therapists (2). Patients were seldom referred from either anaesthetists or psychologists.

Table 4. 8: The median response for patients referred by each healthcare source

Referral source	Median response
GP	1
Orthopaedic	3
Neurologist	3
Psychologist	4
Anaesthetist	4
Rehabilitation Therapist	2
Self-Referral	4
Rheumatologist	1

The respondents were asked about the descriptions that best fit the referral of patients/clients with fibromyalgia. Their responses indicated that 58.0% of patients came to their clinics after trying other forms of treatment. Furthermore, the respondents reported that 32.0% of the patients came to their clinics after all, or nearly all other forms of treatment have been attempted. Table 4.9 and Figure 4.7 present and illustrate the full set data, respectively.

Table 4. 9: How the referral of patients with fibromyalgia is best described

Best describes the patients /clients with Fibromyalgia					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Patients come to me without any previous management	2	3.8	4.0	4.0
	Patients to me at an early stage of their assessment	2	3.8	4.0	8.0
	Patients come to me after other forms of treatment	29	54.7	58.0	66.0
	Patients come to me after all or nearly all, other forms of treatment have been attempted	16	30.2	32.0	98.0
	combination	1	1.9	2.0	100.0
	Total	50	94.3	100.0	
Missing	.	3	5.7		
Total		53	100.0		

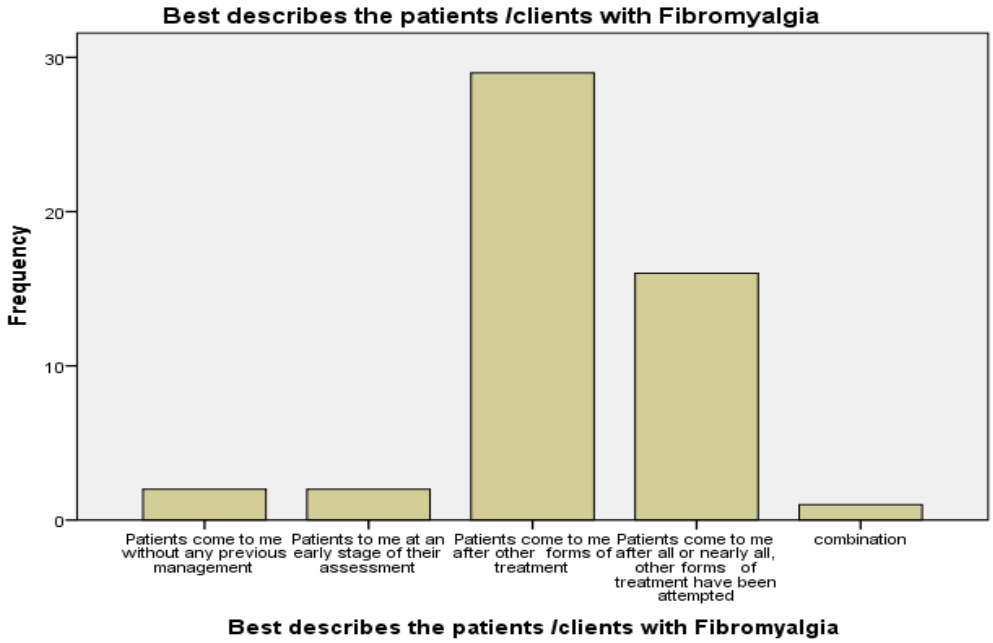

Figure 4. 7: How the referral of patients with fibromyalgia is best described

The respondents were also asked to respond by either 'Yes' or 'No' to whether they considered that the patients/clients they had seen to have fibromyalgia only. It can be seen from Table 4.10 and Figure 4.8 that the responses were fairly equally divided, though a substantial number of respondents considered the patients they had seen to have other diagnoses in addition to fibromyalgia.

Table 4.10: Responses regarding whether patients were considered to have fibromyalgia only.

Patients/clients consider to have fibromyalgia only					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	15	28.3	30.0	30.0
	Yes	35	66.0	70.0	100.0
	Total	50	94.3	100.0	
Missing		3	5.7		
Total		53	100.0		

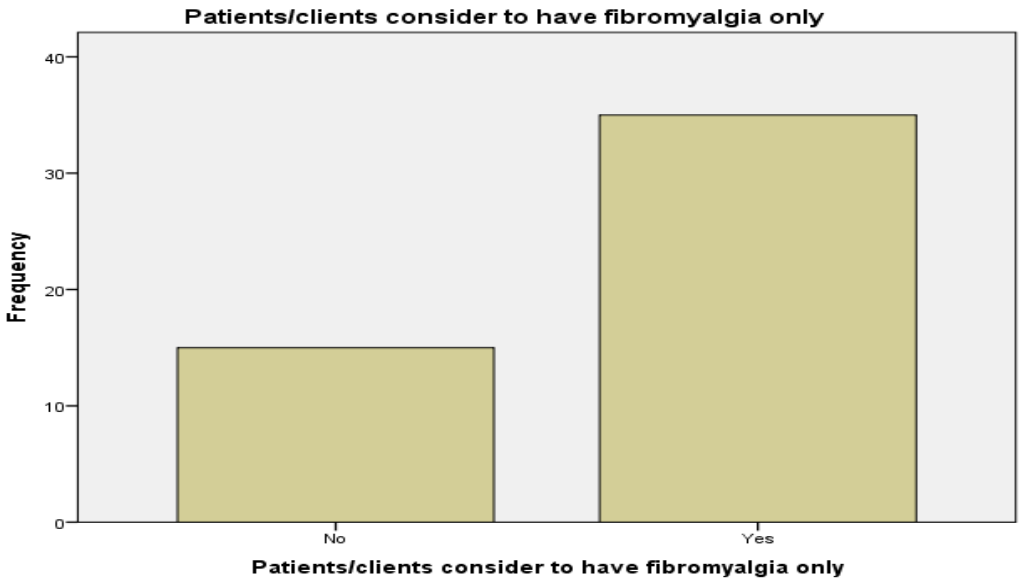

Figure 4.8: Responses regarding whether patients were considered to have fibromyalgia only

The respondents were then asked about patients considered to have co-morbid conditions. Table 4.11 and Figure 4.9 show that most respondents reported depression (37%) and irritable bowel syndrome (IBS) (37%) followed by musculoskeletal pain (neck and back pain, and joint pain).

Table 4.11: Patients considered to have co-morbid conditions

Patients considered to have Co-morbid condition					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	IBS	6	11.3	37.5	37.5
	Depression	6	11.3	37.5	75.0
	Nick and Back pain	3	5.7	18.8	93.8
	Joints pain	1	1.9	6.3	100.0
	Total	16	30.2	100.0	
Missing		37	69.8		
Total		53	100.0		

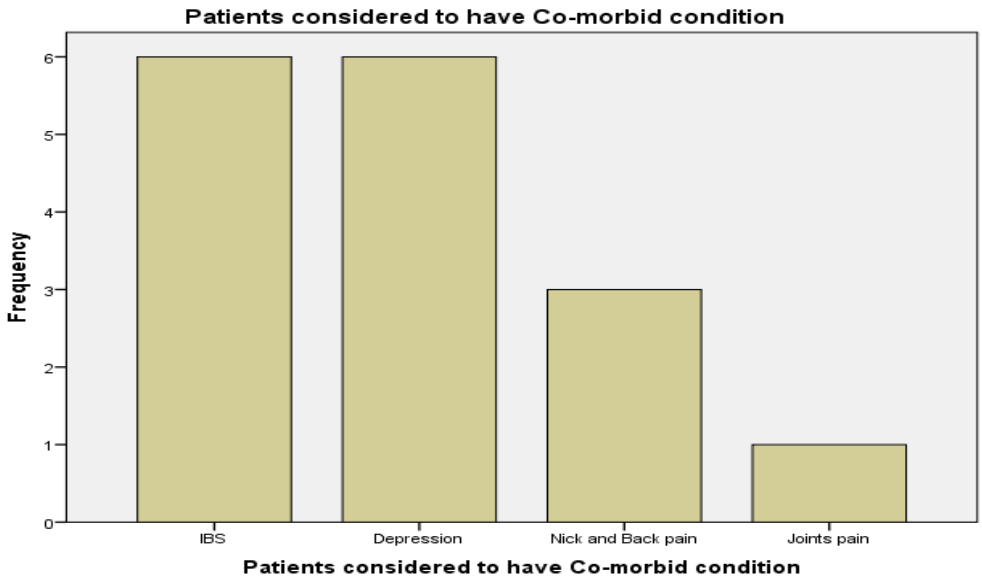

Figure 4.9: Patients considered having co-morbid conditions

Table 4.12 and Figure 4.10 below show that 77.6% of patients were considered to have fibromyalgia under other diagnostic labels. When questioned about these other diagnostic labels, the greatest number of labels pertained to other musculoskeletal conditions, such as chronic neck and back pain (53.6%), followed by chronic fatigue (21.2%), as can be seen from Table 4.13 and Figure 4.11.

Table 4.12: Patients considered having fibromyalgia under other diagnostic labels

Patients consider to have fibromyalgia under other diagnostic labels					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	11	20.8	22.4	22.4
	Yes	38	71.7	77.6	100.0
	Total	49	92.5	100.0	
Missing		4	7.5		
Total		53	100.0		

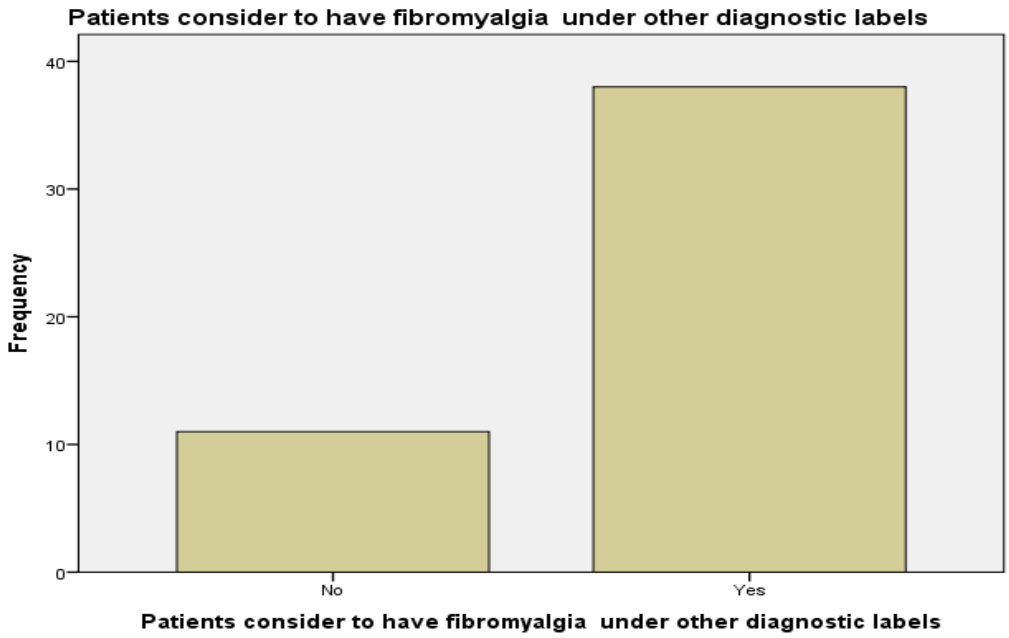

Figure 4.10: Patients considered having fibromyalgia under other diagnostic labels

Table 4.13 shows that 15 patients were seen under chronic neck and low back pain, six under chronic fatigue, and seven under polymyalgia.

Table 4.13: Patients seen under other diagnostic labels

Patients seen under other diagnostic labels					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Chronic Neck & LBP	15	28.3	53.6	53.6
	Chronic Fatigue	6	11.3	21.4	75.0
	Polymyalgia	7	13.2	25.0	100.0
	Total	28	52.8	100.0	
Missing		25	47.2		
Total		53	100.0		

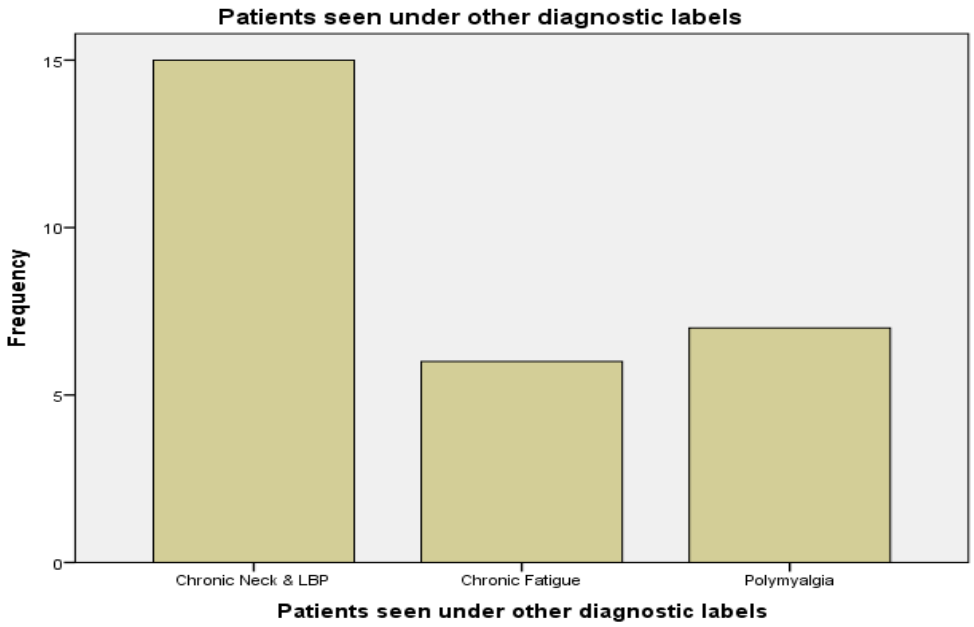

Figure 4. 11: Patients seen under other diagnostic labels

Few respondents reported that the other diagnostic labels included chronic fatigue, , polymyalgia and chronic low back pain (CLBP), cognitive dysfunction, joint hypermobility, degenerative disc disease of the spine (DDD), migraine, and pelvic pain.

4.6.4 Symptoms and functional activity

The subsequent section of the questionnaire related to symptoms and their impact on physical and functional activity. The respondents were asked about the extent to which their patients/clients generally showed an increase in pain as a result of an increase in the level of physical activity. Table 4.14 shows that 26 respondents indicated that physical activity resulted in a severe or very severe increase in pain, while 18 respondents reported a moderate increase in pain. Only one respondents reported a mild increase in pain following physical activity. Figure 4.12 illustrates the full set of data.

Table 4.14: Patients showing an increase in pain as a result of an increase in the level of physical activity.

Patients /clients generally show an increase in pain with an increase in level of physical activity					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Mild	1	1.9	2.0	2.0
	Moderate	18	34.0	36.0	38.0
	Severe	26	49.1	52.0	90.0
	Most severe	5	9.4	10.0	100.0
	Total	50	94.3	100.0	
Missing		3	5.7		
Total		53	100.0		

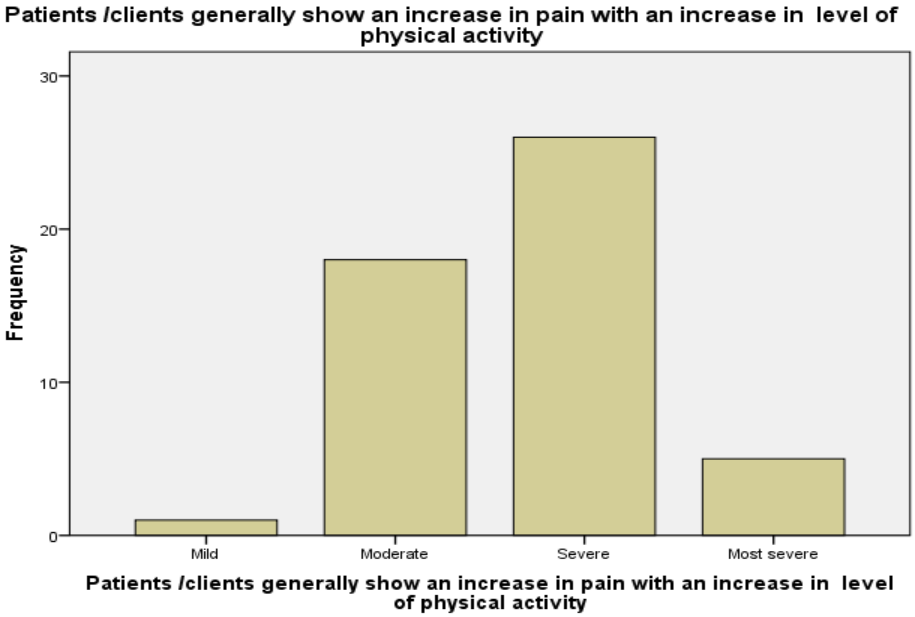

Figure 4.12: Patients showing an increase in pain resulting from an increase in the level of physical activity.

The respondents were then asked about whether their patients/clients used assisted equipment, such as walking aids. Table 4.15 shows that 55.1% of the respondents reported the use of assisted equipment by their patients, while 42.9% reported that such equipment was only sometimes used by their patients.

Table 4.15: Patients using assisted equipment (e.g. walking aids)

Patients /clients use assisted equipment Patients					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	27	50.9	55.1	55.1
	No	1	1.9	2.0	57.1
	Sometimes	21	39.6	42.9	100.0
	Total	49	92.5	100.0	
Missing		4	7.5		
Total		53	100.0		

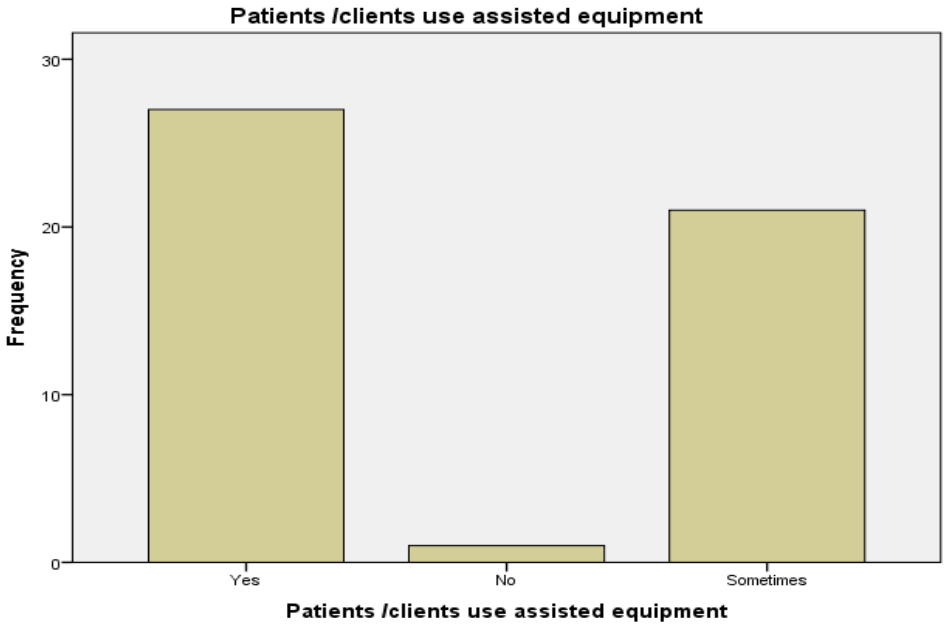

Figure 4. 13 Patients using assisted equipment (e.g. walking aids)

Table 4.16 shows that most of the daily living activities were affected due to fibromyalgia, with 74.0% of respondents reporting that all daily living aspects of their patients' lives were affected. Walking was particularly affected (16%), as illustrated in Figure 4.14.

Table 4.16: Daily living aspects/activities most affected by fibromyalgia

Patients daily living are most affected due to chronic widespread pain (fibromyalgia)					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Walking	8	15.1	16.0	16.0
	Running	1	1.9	2.0	18.0
	Shopping	1	1.9	2.0	20.0
	None of these	3	5.7	6.0	26.0
	All Of These	37	69.8	74.0	100.0
	Total	50	94.3	100.0	
Missing		3	5.7		
Total		53	100.0		

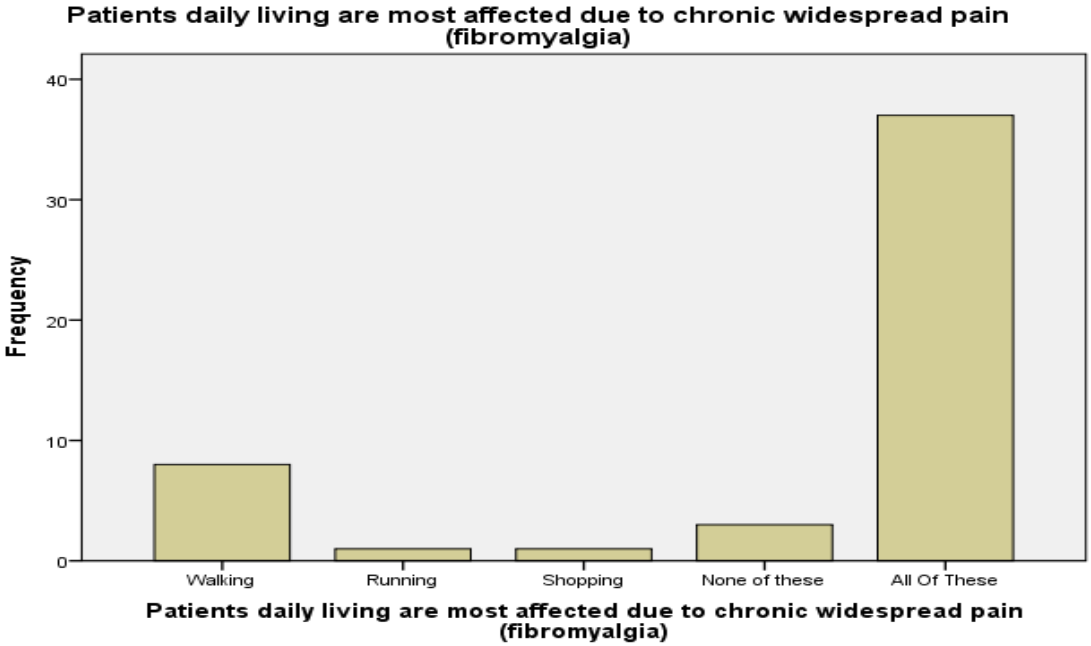

Figure 4.14: Daily living aspects/activities most affected by fibromyalgia

4.6.5 Clinical features

The frequency of presentation of the various clinical features of fibromyalgia were reported using a Likert scale, where 1= always, 2= often, 3=sometimes, 4= seldom, and 5= never. The median value for each of clinical feature is shown in the Table 4.17. It can be seen that the occurrences of most clinical features were rated as “always” or “often”. Furthermore, the table shows that the lowest median response was for peripheral circulatory, followed by loss of joint range. On the other hand, the most frequent clinical features reported were pain, excessive fatigue, psychological features

and tenderness on palpation, followed by loss of function, localised pain, loss of muscle power and stiffness,.

Table 4. 17: Median responses for frequency of clinical features presented by patients

Clinical Feature	Median response
Generalised pain	1
Localised pain	2
Tenderness on palpation	1
Excessive fatigue	1
Loss of muscle power/endurance	2
Loss of joint range	3
Stiffness	2
Loss of function	1.5
Psychological aspects	1
Peripheral circulatory	4
Others	2

The respondents were also asked to identify the clinical feature they found to be most important to the patient. Table 4.18 and Figure 4.15 demonstrate that pain was considered to be the most important symptom to patients, followed by fatigue. Pain was reported by 65.% of the respondents, fatigue by 28.6%, and loss of function as a result of pain and fatigue by 6%.

Table 4. 18: Most important clinical features to patients

Most important clinical features to FMS patients					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Pain	32	60.4	65.3	65.3
	Fatigue,Tiredness	14	26.4	28.6	93.9
	Loss of Function	3	5.7	6.1	100.0
	Total	49	92.5	100.0	
Missing	.	4	7.5		
Total		53	100.0		

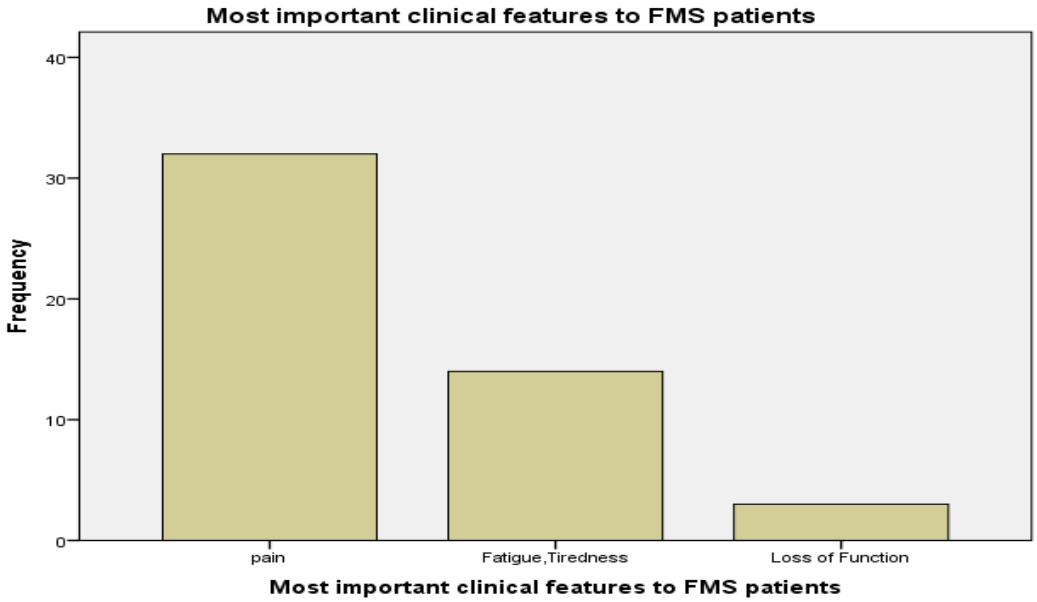

Figure 4. 15: Most important clinical features to patients

4.6.6 Primary symptoms: pain assessment and measurement

The questionnaire also asked the respondents if they routinely assessed or measured pain, and how they assessed or measured it. Table 4.19 shows that 19 respondents used a numerical rating scale (39.6%), 16 respondents reported using multiple measurement scales (33.3%), six did not routinely use a measure for pain intensity (12.5%), three respondents used verbal rating scales (6.3%), and two used a visual analogue scale (4.2%). Only one respondent used the McGill Pain Questionnaire. Figure 4.16 illustrates the full set of this data.

Table 4.19 Measurement of pain intensity

Measurement of pain intensity of fibromyalgia patients					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Numerical rating scale (e.g. 1-10)	19	35.8	39.6	39.6
	Verbal rating scales (e.g. severe, moderate	3	5.7	6.3	45.8
	Visual analogue scale	2	3.8	4.2	50.0
	McGill Pain Questionnaire (long or short form	1	1.9	2.1	52.1
	Other	1	1.9	2.1	54.2

	Do not routinely measure pain intensity	6	11.3	12.5	66.7
	Multiple	16	30.2	33.3	100.0
	Total	48	90.6	100.0	
Missing		5	9.4		
Total		53	100.0		

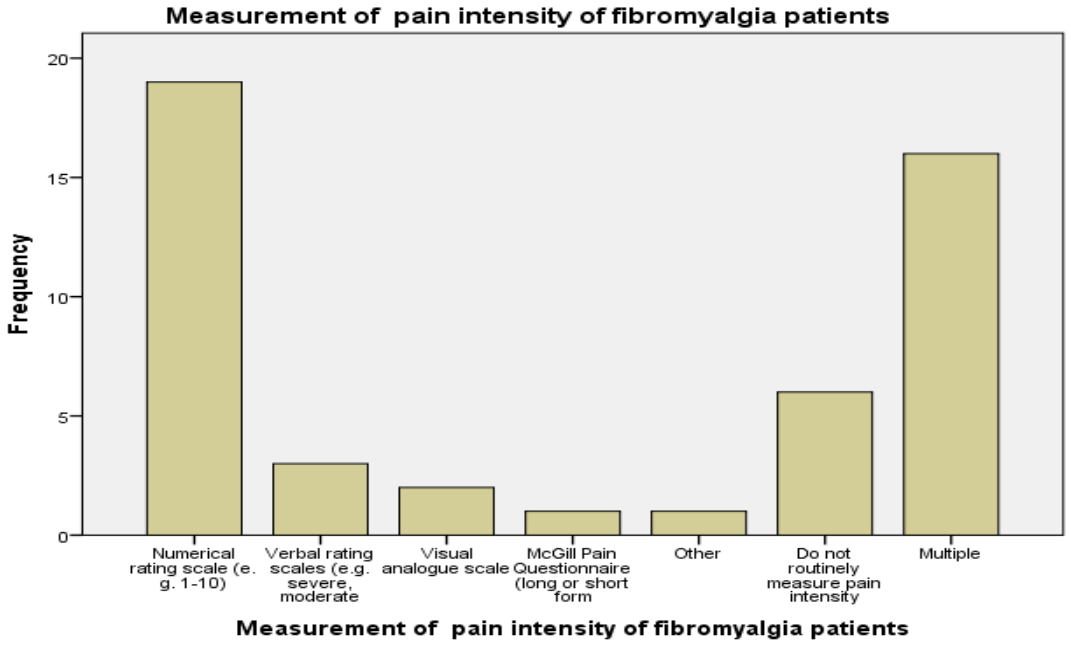

Figure 4.16: Measurement of pain intensity.

The participants were also asked if they routinely assessed or measured other dimensions of pain besides intensity pain, and how they assessed or measured them. Responses in Table 4.20 show that five respondents used the Brief Pain Inventory (BPI), while 47 respondents did not routinely measure other dimensions of pain for people with fibromyalgia.

Table 4. 20: Measurement of pain dimensions other than its intensity.

Measurement of pain dimensions other than its intensity.					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	BPI	5	9.4	100.0	100.0
Missing		47	88.7		
	System	1	1.9		
	Total	48	90.6		
Total		53	100.0		

The respondents were subsequently asked if they used standardised assessment scales for fibromyalgia patients. Table 4.21 indicates that the majority of respondents (50.%) reported that they did not use a standardised assessment for fibromyalgia, while 50% reported that they used standardised assessment scales.

Table 4.21: Use of standardised assessment scales or measures for fibromyalgia patients

Standardised assessment scales or measures for fibromyalgia patients					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	23	43.4	50.0	50.0
	Yes	23	43.4	50.0	100.0
	Total	46	86.8	100.0	
Missing		7	13.2		
Total		53	100.0		

Table 4.22 and Figure 4.17 show that 45.5% of the respondents reported that they used the Brief Pain Inventory (BPI) as a standardised assessment scale, while 31.8% used the Hospital Anxiety and Depression Score (HADS). On the other hand, only 22.7% of the respondents reported the use of Pain Self-Efficacy Questionnaire (PSEQ) as a standardised assessment scale.

Table 4. 22: Use of standardised assessment measures

Use of standardised assessment measures					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	HADS	7	13.2	31.8	31.8
	BPI	10	18.9	45.5	77.3
	PSEQ	5	9.4	22.7	100.0
	Total	22	41.5	100.0	
Missing		31	58.5		
Total		53	100.0		

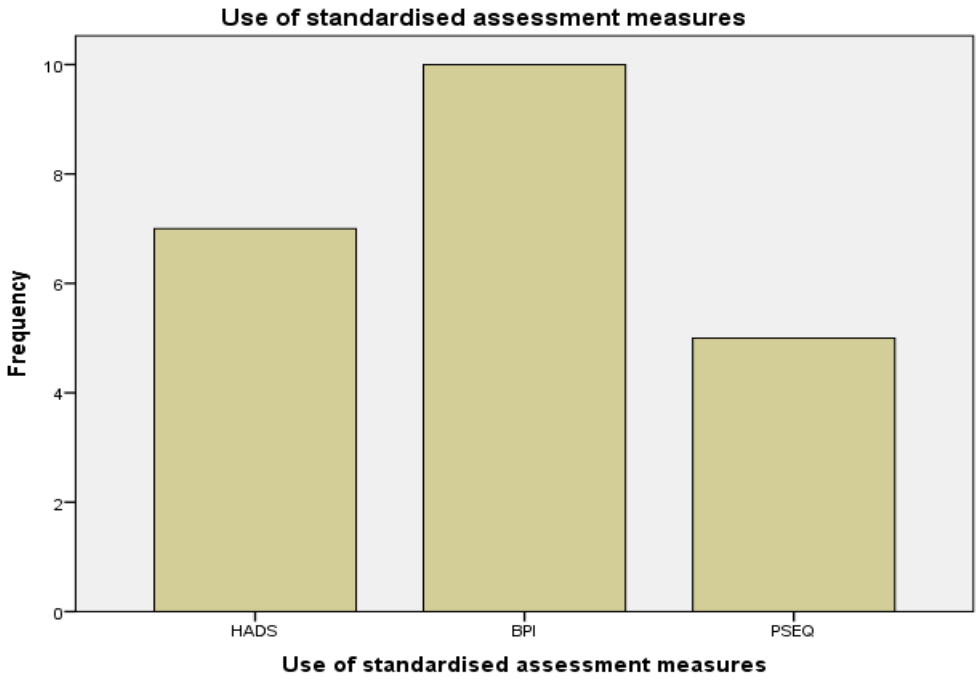

Figure 4.17: Use of standardised assessment measures

4.6.7 Pharmacological approaches: medication prescribed to patients with FMS

The respondents were asked about the medications they prescribed to FMS patients in their practice. Table 4.23 and Figure 4.18 show that 85.7% of the respondents used a combination of medications. Furthermore, the data shows that 12.2% of the respondents did not prescribe medications, while amitriptyline was rarely prescribed by the respondents to fibromyalgia patients.

Table 4.23: Medications prescribed to patients with fibromyalgia

Medications prescribed to patients with fibromyalgia					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Amitriptyline	1	1.9	2.0	2.0
	Combination	42	79.2	85.7	87.8
	Do not Prescribe	6	11.3	12.2	100.0
	Total	49	92.5	100.0	
Missing		4	7.5		
Total		53	100.0		

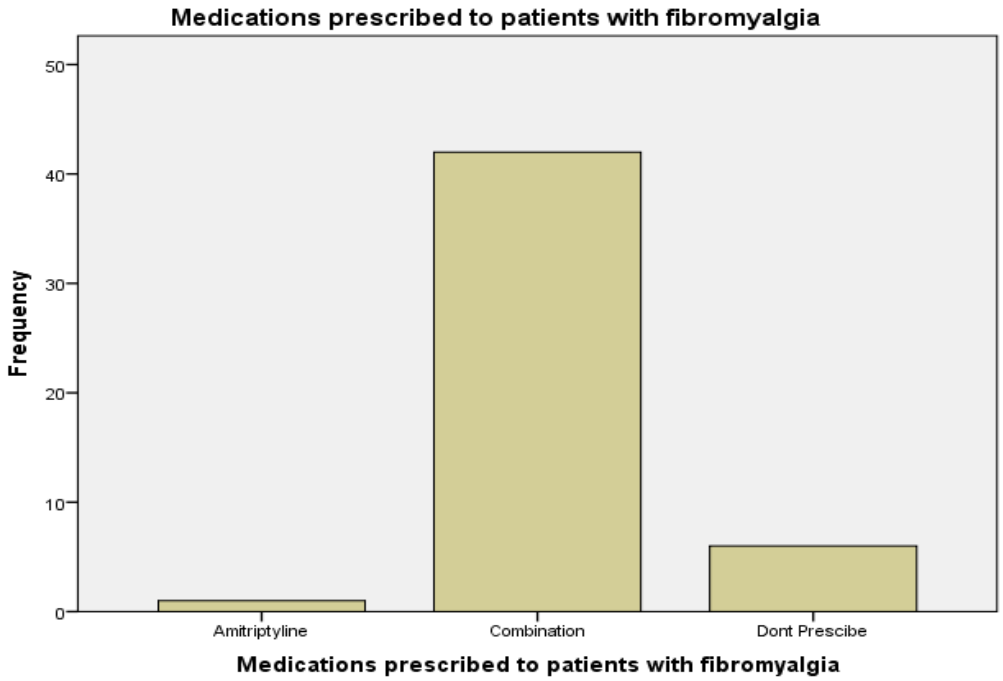

Figure 4. 18 : Medications prescribed to patients with fibromyalgia.

Table 4.24 shows that 59.2% of the respondents reported that patients sometimes attended their clinics with medications specifically for their symptoms, while 16.3% reported that patients attended with no medications. Additionally, 24.5% of the respondents reported that patients attended their clinics with medications specifically for their symptoms. The full set of data relating to this questions is illustrated in Figure 4.19

Table 4.24: Patients presenting with medications specifically for their symptoms.

Patients consider to have fibromyalgia, come without medications specifically for their symptoms					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	12	22.6	24.5	24.5
	No	8	15.1	16.3	40.8
	Sometimes	29	54.7	59.2	100.0
	Total	49	92.5	100.0	
Missing		4	7.5		
Total		53	100.0		

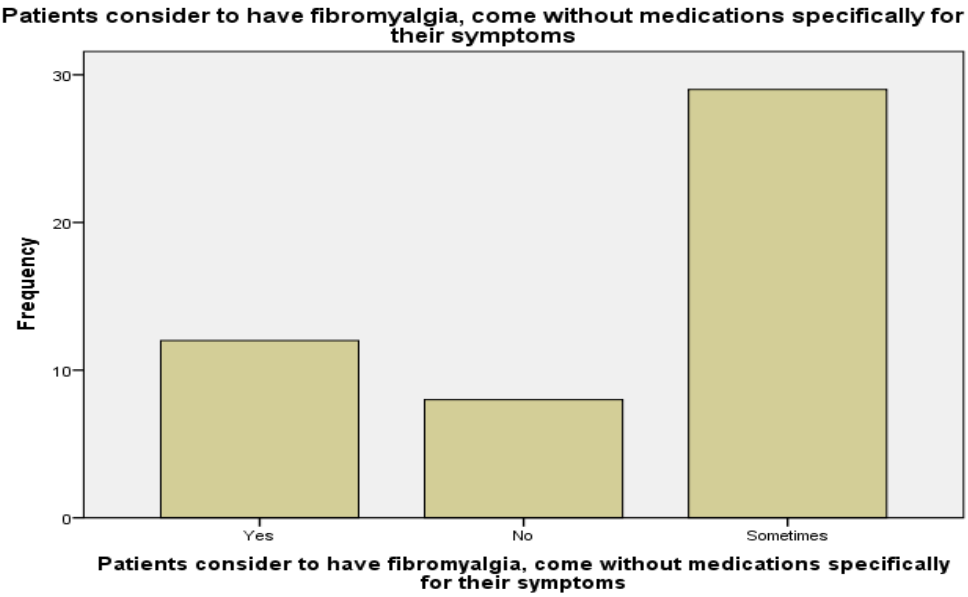

Figure 4. 19: Patients presenting with medications specifically for their symptoms

4.6.8 Non-pharmacological interventional approaches

A number of non-pharmacological interventional approaches were ranked by the respondents on a Likert scale in terms of frequency of use, where 1=always/almost always, 2=often, 3=sometimes, 4=seldom, and 5=never/almost never. The median responses for these interventional approaches are shown in Table 4.25.

Table 4.25: Median responses for use of non-pharmacological interventional approaches

Intervention	Median Response
Stretching exercise	2
Aerobic exercise	3
Graded exercise programme	2
Group exercise	3
Hydrotherapy	3
Postural re-education	3
Functional activity re-education	2
Cognitive behavioural therapy	2
Relaxation	2
Acupuncture	3
Ergonomic evaluation	5
TENS	3
Ultrasound	5
Manual therapy	5
Massage	5
Energy conservation	3.5

Table 4.25 indicates that the most frequently used interventions were stretching exercises, graded exercise programmes, functional activity re-education, cognitive behavioural therapy, and relaxation. These five interventions were frequently reported, followed by aerobic exercise, hydrotherapy, postural re-education and TENS. In contrast, ergonomic evaluation, ultrasound, manual Therapy and massage were seldom used.

4.6.9. The use of a specific management programme by HCPs for FMS

The respondents were asked about the use of a specific management programme for fibromyalgia. Table 4.26 shows that 62.0 % of the respondents had a management programme for chronic pain in general, but only 12.0% of respondents had a management programme specifically tailored for fibromyalgia. The remainder of respondents had no specific management programmes. The responses are illustrated in Figure 4.20.

Table 4.26: Use of a specific management programme for fibromyalgia

Use of a specific management programme for fibromyalgia					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	13	24.5	26.0	26.0
	Yes, for chronic pain patients in general	31	58.5	62.0	88.0
	Yes, specifically for fibromyalgia patients	6	11.3	12.0	100.0
	Total	50	94.3	100.0	
Missing		3	5.7		
Total		53	100.0		

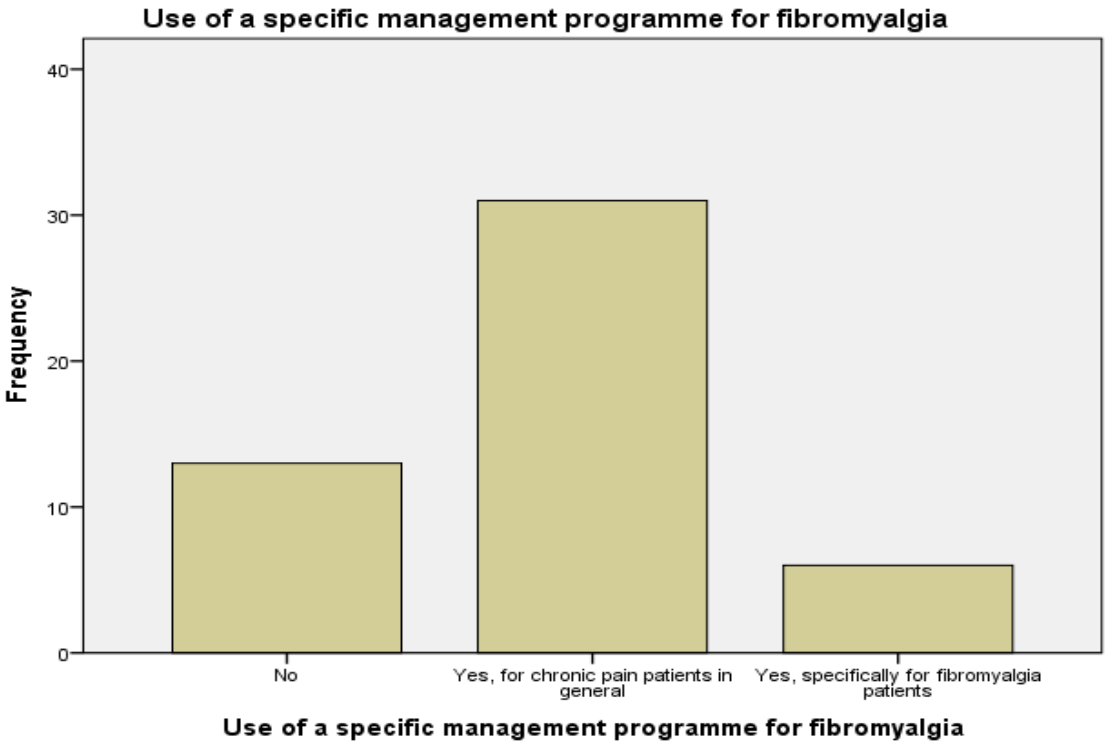

Figure 4.20: Use of a specific management programme for fibromyalgia

The respondents were then asked regarding the components of the specific management programmes they used for fibromyalgia. Table 4.27 shows that, of the respondents, physiotherapy registered the most common use (41.7%), followed by the use of lidocaine infusion (33.3%), with 16.7% of respondents reporting the use of CBT.

Table 4.27: Frequency of prescribing specific management programmes for fibromyalgia

Frequency of prescribing specific management programmes for fibromyalgia					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Psychological Group Sessions	1	1.9	8.3	8.3
	Physiotherapy	5	9.4	41.7	50.0
	CBT	2	3.8	16.7	66.7
	Lidocaine infusion	4	7.5	33.3	100.0
	Total	12	22.6	100.0	
Missing		41	77.4		
Total		53	100.0		

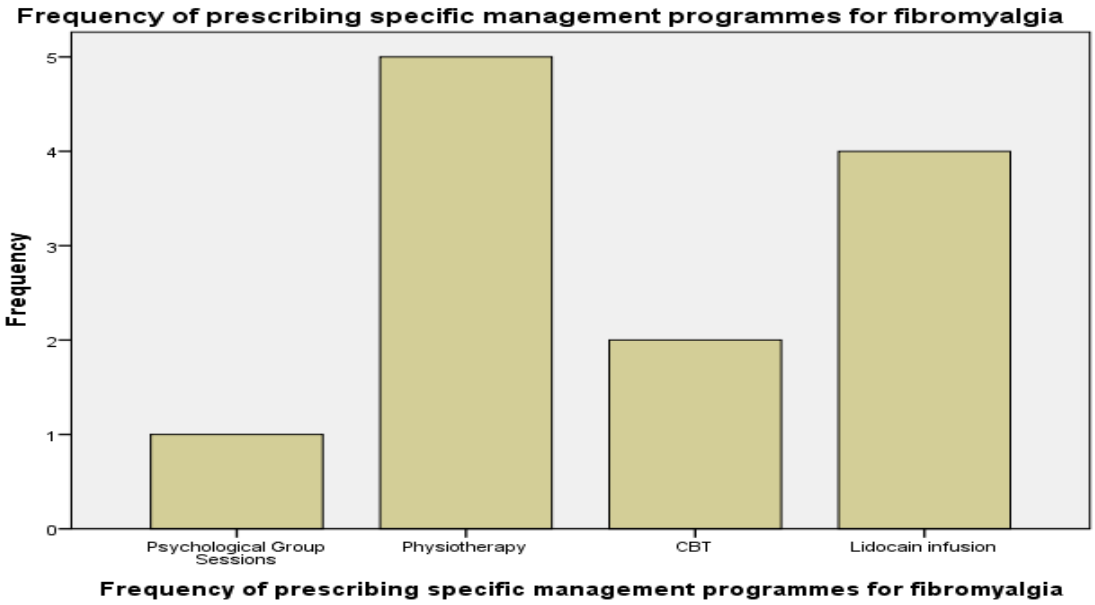

Figure 4. 21: Frequency of prescribing specific management programmes for fibromyalgia.

The respondents were subsequently queried about the responsiveness of fibromyalgia patients to the interventional approaches. The respondents provided their answers using a Likert scale, where 1= extremely responsive, 2= very responsive, 3= moderately responsive , 4= quite unresponsive, and 5= extremely unresponsive. As can be seen from Table 4.28, 62% of the respondents reported moderate response to interventional approaches, while 28. % reported their patients to be quite unresponsive to the interventional approaches. The full set of results for this question is illustrated in Figure 4.22.

Table 4. 28: Responsivity of fibromyalgia patients to interventional approaches

Responsivity of fibromyalgia patients to interventional approaches					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Extremely responsive	1	1.9	2.0	2.0
	Very responsive	2	3.8	4.0	6.0
	Moderately responsive	31	58.5	62.0	68.0
	Quite unresponsive	14	26.4	28.0	96.0
	Extremely unresponsive	2	3.8	4.0	100.0
	Total	50	94.3	100.0	
Missing		3	5.7		
Total		53	100.0		

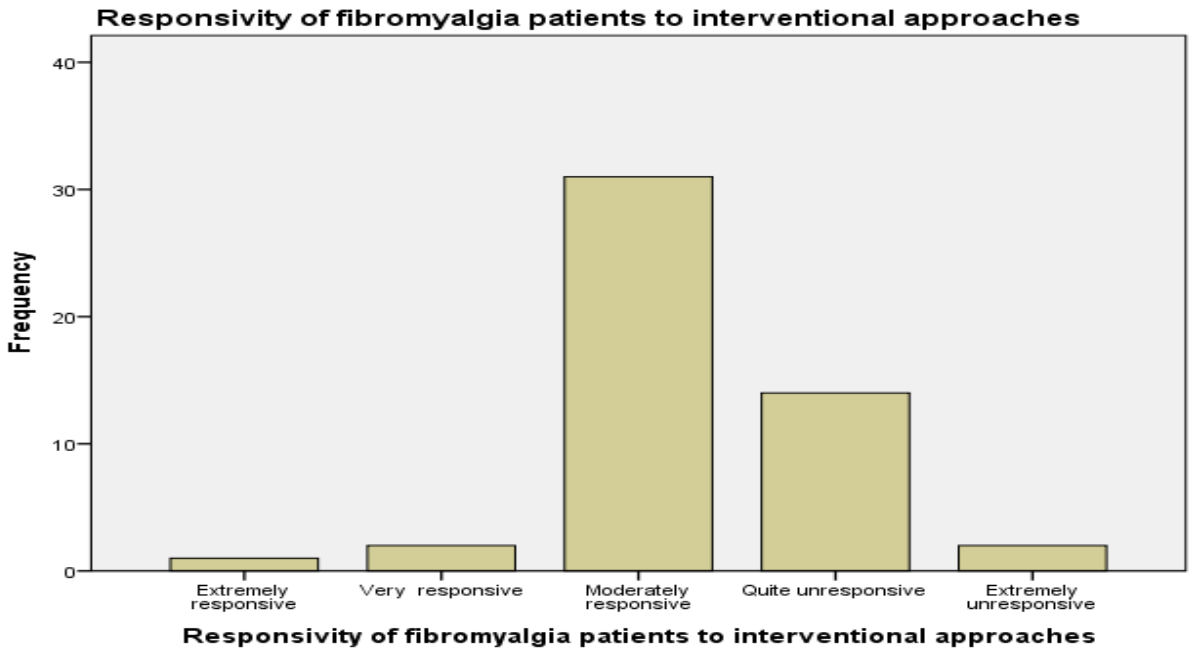

Figure 4. 22: Responsivity of fibromyalgia patients to interventional approaches

4.6.10 Aims of fibromyalgia rehabilitation programmes

The respondents were asked about what they hoped to achieve from a fibromyalgia rehabilitation programme.

Table 4. 29: Breakdown of the reported aims of rehabilitation programmes

Aims of fibromyalgia rehabilitation programmes					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Improve Physical Function	27	50.9	65.9	65.9
	Cope with pain	10	18.9	24.4	90.2
	Understanding the Condition	4	7.5	9.8	100.0
	Total	41	77.4	100.0	
Missing		12	22.6		
Total		53	100.0		

Table 4.29 shows a breakdown of the reported aims of a rehabilitation programme. 27 respondents (65.9%) reported that improving physical function for fibromyalgia patients was the main aim, while coping with pain was reported as the main aim by 10 respondents (24.4%). A small number of respondents indicated that improving the

patients' understanding of the condition was their main target. Figure 4.23 depicts the responses to this question in visual form.

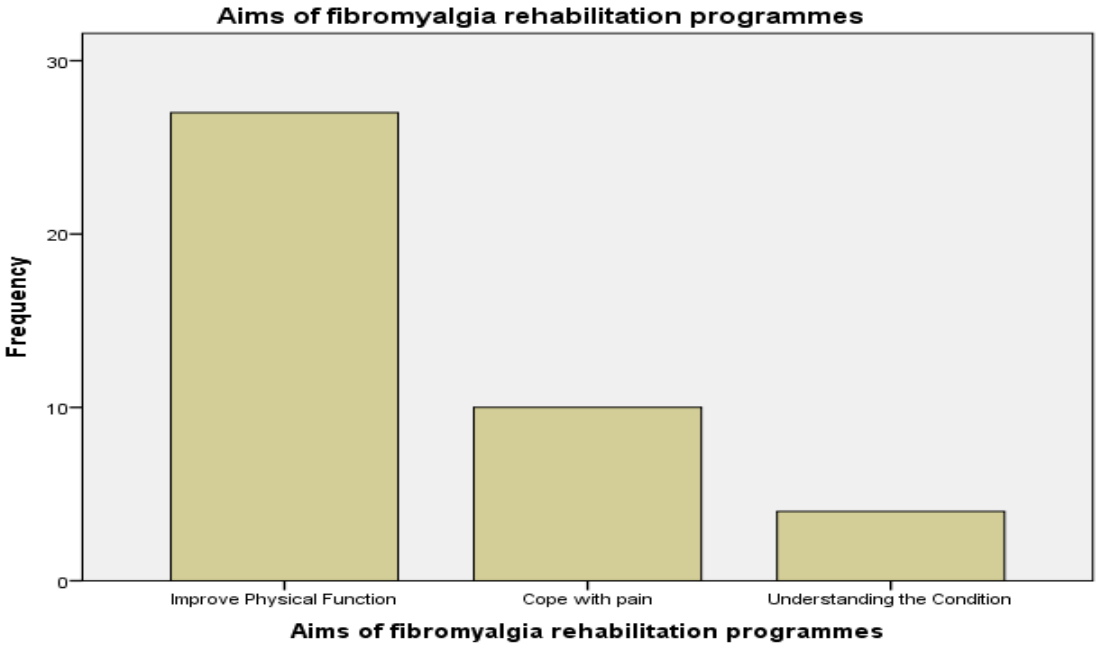

Figure 4. 23: The reported aims of fibromyalgia rehabilitation programmes

4.6.11 Clinicians' attitudes and opinions

The attitudes and opinions of the respondents on FMS patients were rated on a Likert scales, where 1= strongly agree, 2= agree, 3= neither, 4= disagree, and 5= strongly disagree. The statements and the median responses provided for them by the respondents are shown in Table 4.30. It can be seen that there was agreement with the psychological involvement in the condition, the importance of improving the functional ability of patients, and that the diagnosis is made once all other diagnoses have been tried and rejected. Neutral responses were obtained regarding patients being well informed on their condition, their ability to self-manage, and on if treatment must not aggravate pain.

Table 4.30: Median responses to attitudinal questions

Statement about FMS patients	Median Response
Patients have considerable psychological overlay	2
Treatment must not aggravate patients' pain	4
Restoring function is more important than treating pain	2
The diagnosis is made once all others diagnoses have been tried and rejected	2
Patients are generally well informed on their condition	4
Patients are able to self-manage their condition	3

4.7 Section B: Fibromyalgia survey (Libyan)

This section reports upon the parallel survey carried out in Libya, using the same survey.

4.7.1 Data collection

The questionnaires, along with invitations, consent forms and information sheets, were handed to a convenience sample of participants, recruited through clinical contacts. In total 25 participants agreed to participate in the study, however, only 15 respondents returned the questionnaire with the consent form to researcher. The respondents included eight physicians, six physiotherapists, and 1 rheumatologist. The setting for this survey was in two Libyan cities (Tripoli (the capital city), and Zawia). This survey did not require ethical approval from the Libyan health authority because the researcher followed the European guide for research.

4.7.2 Data analysis

4.7.2.1 Demographic data

Table 4.7.1 and Figure 4.7.1 show the breakdown of respondents by city.

Table 4.7. 1: Breakdown of respondents by city

City					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Tripoli	10	62.5	66.7	66.7
	Zawia	5	31.3	33.3	100.0
	Total	15	93.8	100.0	

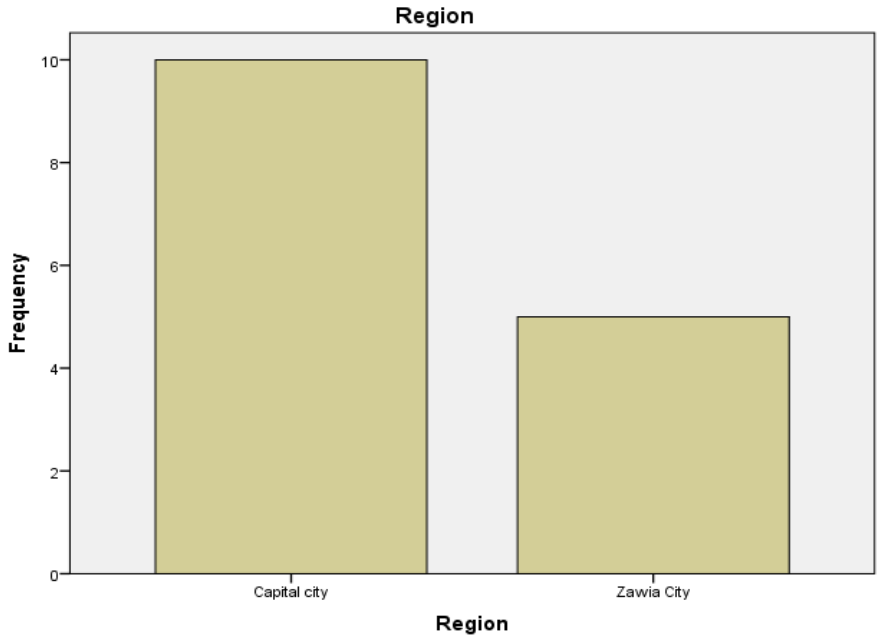

Figure 4.7.1: Breakdown of respondents by city

Table 4.7.2 presents the professional specialties of the respondents. The table shows that eight respondents were medicine physicians (53.3%), six were physiotherapists (40.0%), and one was a rheumatologist.

Table 4.7.2: Professional specialties of the respondents

Profession					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Rheumatologist	1	6.3	6.7	6.7
	Physiotherapist	6	37.5	40.0	46.7
	Medicine Physician	8	50.0	53.3	100.0
	Total	15	93.8	100.0	

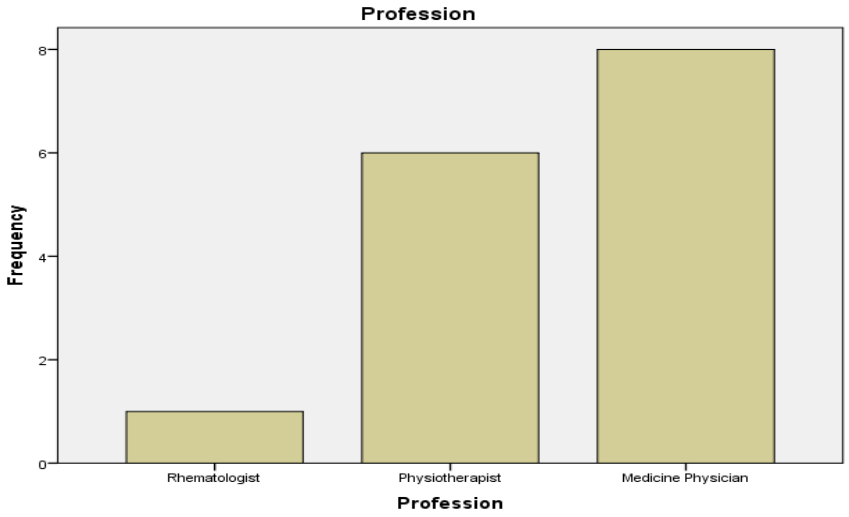

Figure 4.7.2: Respondents per professional specialty

Table 4.7.3 shows that the clinical setting for the majority of the respondents was inpatient (46.7%), followed by private (33.3%). Two respondents were based in outpatient, and one in community.

Table 4.7.3: Clinical settings of the respondents

Clinical Setting					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Inpatient	7	43.8	46.7	46.7
	Outpatient	2	12.5	13.3	60.0
	Community	1	6.3	6.7	66.7
	Private	5	31.3	33.3	100.0
	Total	15	93.8	100.0	

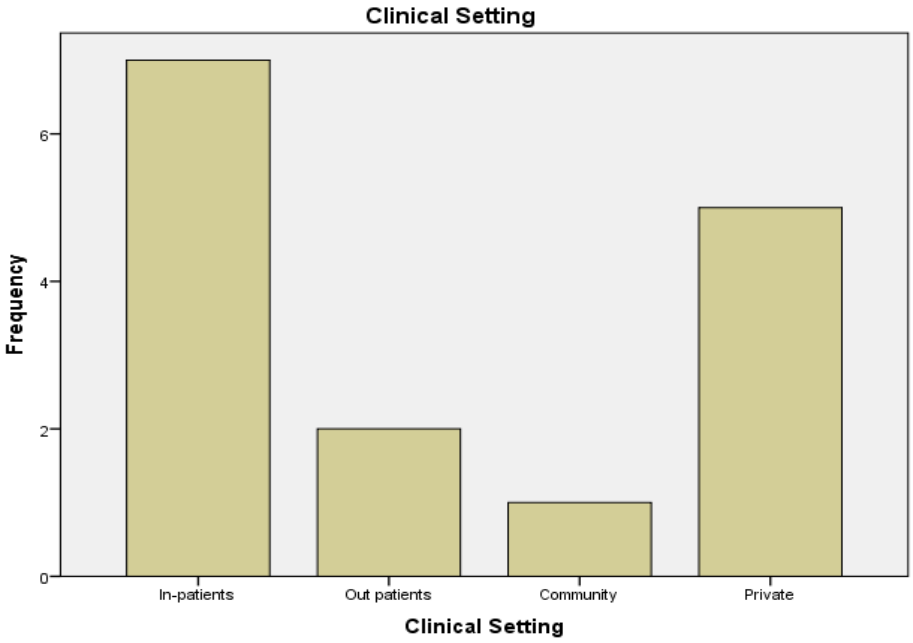

Figure 4.7 3: Clinical settings of the respondents

4.7.2.2. Diagnosis

Table 4.7.4 shows that when the respondents were asked if they had seen patients that fit the description of fibromyalgia in last 12 months, 80% responded that they had seen patients who more or less fitted the description, while 20% reported that they had seen patients who closely fit the description.

Table 4.7.4: Proportion of respondents who saw patients fitting description of fibromyalgia

Proportion of respondents who saw patients fitting description of fibromyalgia in the last 12 months					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes, I have seen patients who closely fit this description	3	18.8	20.0	20.0
	Yes, I have seen patients/clients who more or less	12	75.0	80.0	100.0
	Total	15	93.8	100.0	

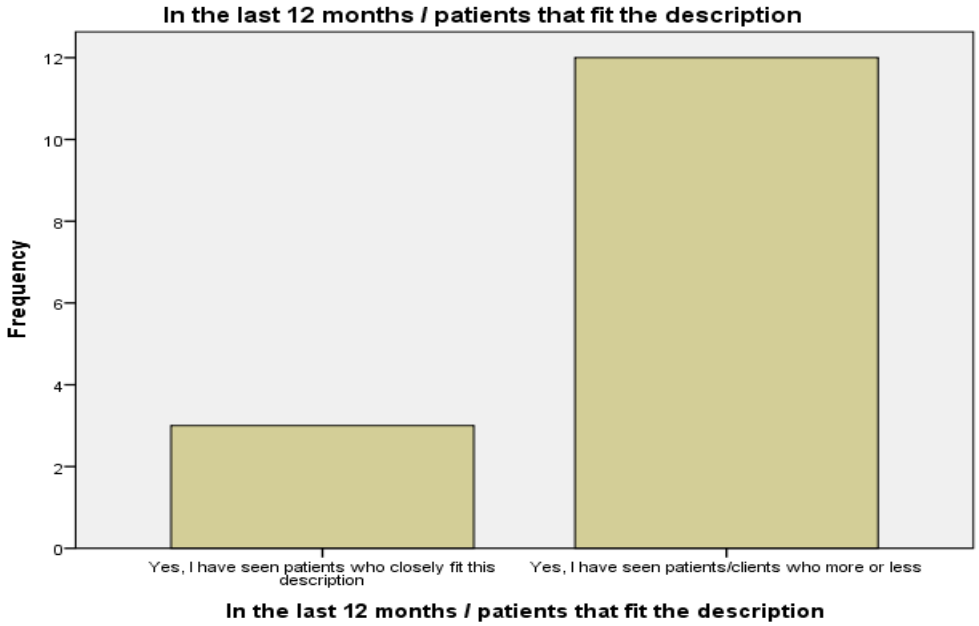

Figure 4.7. 4: Proportion of respondents who saw patients fitting description of fibromyalgia

The respondents were then asked about the number of new patients fitting the description of fibromyalgia who attended their clinic in the last 12 months. Table 4.7.5 shows that 73.3% of the respondents reported that 1-4 new patients per month attended their practice; while 20% reported 5-9 new patients per months. Figure 4.6.5 illustrates the respondents' answers to this question.

Table 4.7.5: Number of new fibromyalgia patients attending the respondents' clinics in the last 12 months

New patients/clients fitting the description of fibromyalgia in the last 12 months					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1-4 patients per month	11	68.8	73.3	73.3
	5-9 patients per month	3	18.8	20.0	93.3
	10-15 patients per month	1	6.3	6.7	100.0
	Total	15	93.8	100.0	

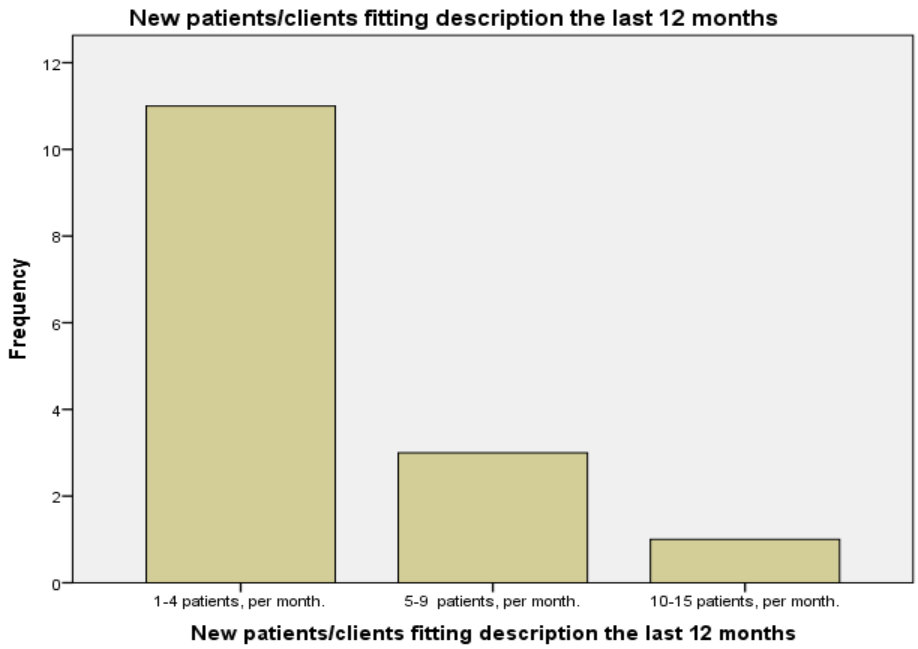

Figure 4.7.5: Number of new fibromyalgia patients attending the respondents' clinics in the last 12 months

The respondents were asked regarding the proportion of patients who had a diagnosis of fibromyalgia. 40% of the respondents stated that there were no patients attending their practice with a diagnosis of fibromyalgia. Furthermore, the respondents reported that patients who fulfilled the definition provided on the questionnaire were diagnosed with chronic pain, such as low back pain. The full results of this question are shown in Table 4.7.6 are illustrated in Figure 4.7.6.

Table 4.7.6: Proportion of patients who had a diagnosis of fibromyalgia

Proportion of patients diagnosis of FM					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	More than half of them	1	6.3	6.7	6.7
	About half of them	4	25.0	26.7	33.3
	Less than half of them	1	6.3	6.7	40.0
	Almost none of them	3	18.8	20.0	60.0
	None of them	6	37.5	40.0	100.0
	Total	15	93.8	100.0	

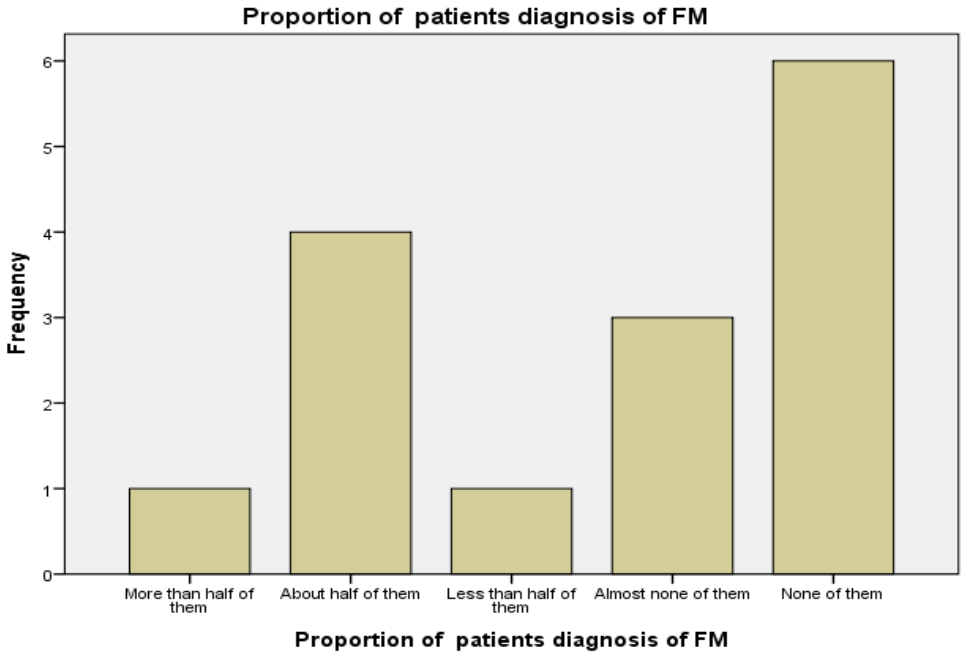

Figure 4.7.6: Proportion of patients who had a diagnosis of fibromyalgia

Referral sources of FMS patients were ranked by the respondents on a Likert scale, where 1= often, 2=sometimes, 3= seldom, and 4 =never. As can be seen from Table 4.7.7, the most frequent referral source indicated by the respondents was rheumatologists, followed by general practitioners, orthopaedics, and self-referrals, which all had a median rank of 2. The least frequent referral sources were anaesthetists and psychologists.

Table 4.7.7: The median response for patients' referral sources

Referral source	Median response
GP	2
Orthopaedic	2
Neurologist	2.5
Psychologist	4
Anaesthetist	4
Rehabilitation Therapist	3
Self-Referral	2
Rheumatologist	1.5

The respondents were also asked regarding what best describes the patients regarding their previous management of the condition. 33.3% of the respondents reported that patients attended their practices without any previous management, while an identical percentage of respondents reported that patients had some other forms of treatment before attending their clinics. Table 4.7.8 and Figure 4.7.7 present the full set of respondents' answers.

Table 4.7. 8:How referral of patients with fibromyalgia is best described

What best describes the patients/clients in terms of previous management					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Patients come to me without any previous management	5	31.3	33.3	33.3
	Patients come to me at an early stage of their assessment	1	6.3	6.7	40.0
	Patients come to me after other forms of treatment	5	31.3	33.3	73.3
	Patients come to me after all, or nearly all other forms of treatment have been attempted	3	18.8	20.0	93.3
	Compound	1	6.3	6.7	100.0
	Total	15	93.8	100.0	

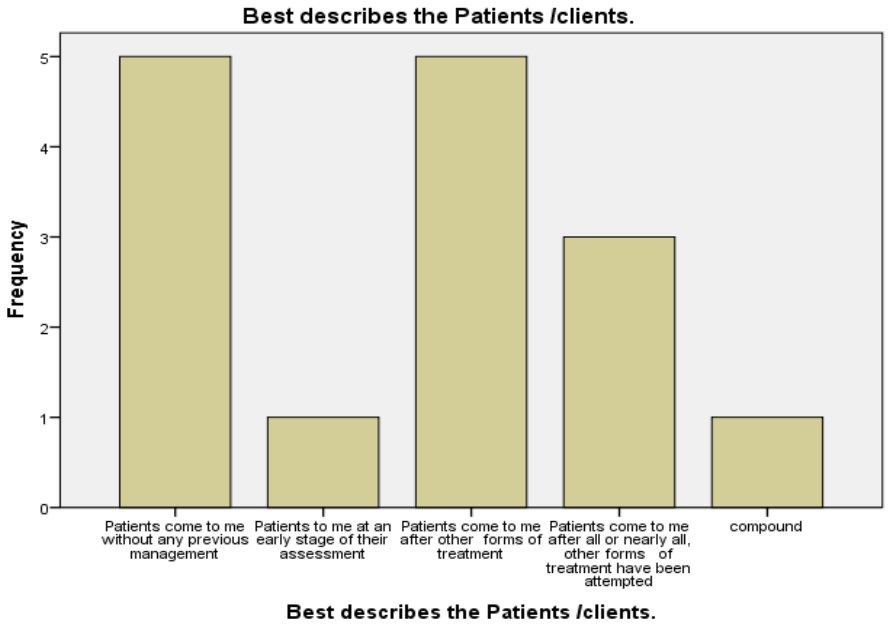

Figure 4.7. 7: How referral of patients with fibromyalgia is best described

The respondents were subsequently asked if patients were considered to have fibromyalgia only. Table 4.7.9 shows that 80% of the respondents reported that patients were considered to have other diagnoses in addition to fibromyalgia.

Table 4.7. 9: Proportion of patients considered by respondents to as have fibromyalgia only

Patients/clients considered to have fibromyalgia only					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	12	75.0	80.0	80.0
	Yes	3	18.8	20.0	100.0
	Total	15	93.8	100.0	

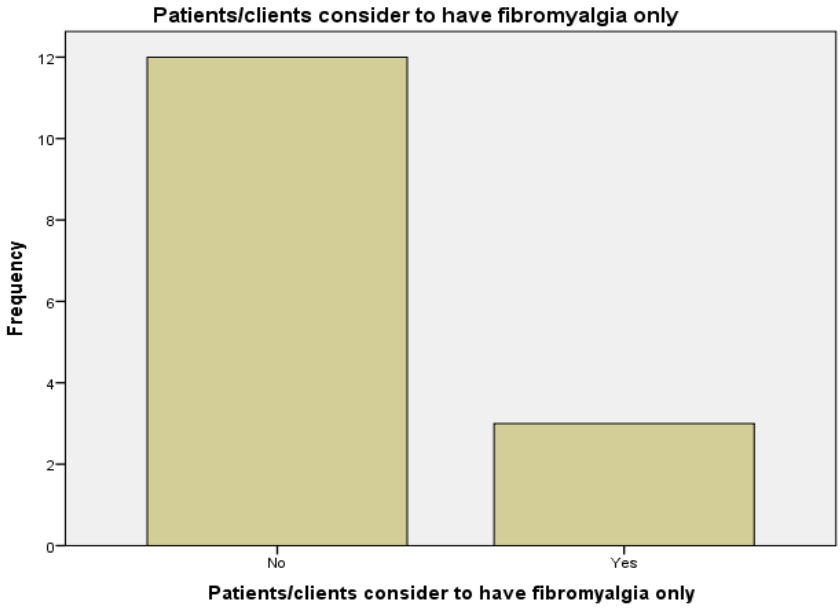

Figure 4.7. 8: Proportion of patients considered as having fibromyalgia only

Table 4.7.10 and Figure 4.7.9 show that the most frequent co-morbid condition reported by respondents for patients who attended their clinics was neck and back pain, followed by joint pain.

Table 4.7. 10: Patients considered as having co-morbid conditions

Co-morbid condition					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Neck and back pain	7	43.8	77.8	77.8
	Joint pain	2	12.5	22.2	100.0
	Total	9	56.3	100.0	

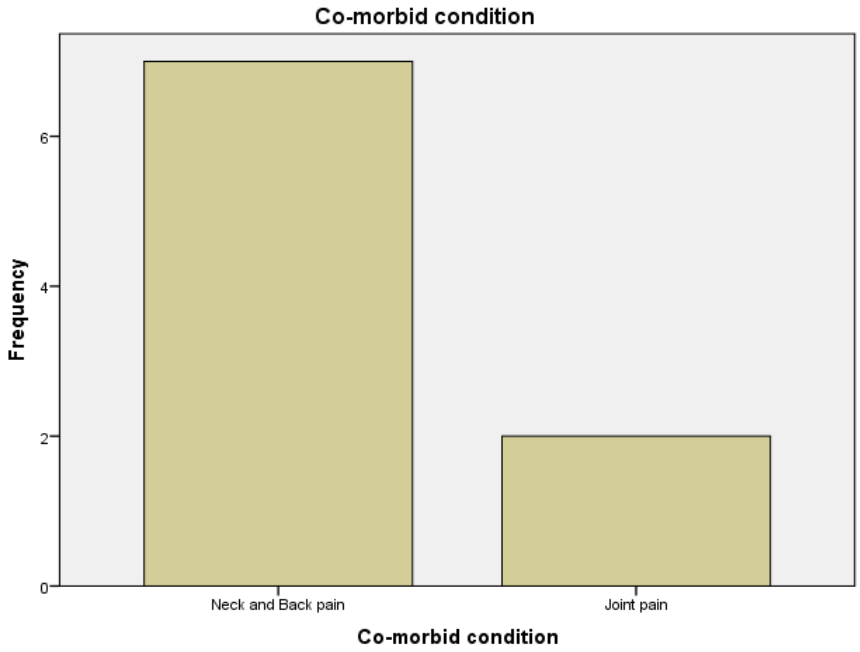

Figure 4.7. 9: Patients considered as having co-morbid conditions.

The respondents were also asked if patients were considered to have fibromyalgia under other diagnostic labels. Table 4.7.11 and Figure 4.7.10 show that 60% of responses were “No” and 40% were “Yes”.

Table 4.7.11: Patients considered by respondents to have fibromyalgia under other diagnostic labels

Patients/clients have fibromyalgia under other diagnostic labels					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	9	56.3	60.0	60.0
	Yes	6	37.5	40.0	100.0
	Total	15	93.8	100.0	

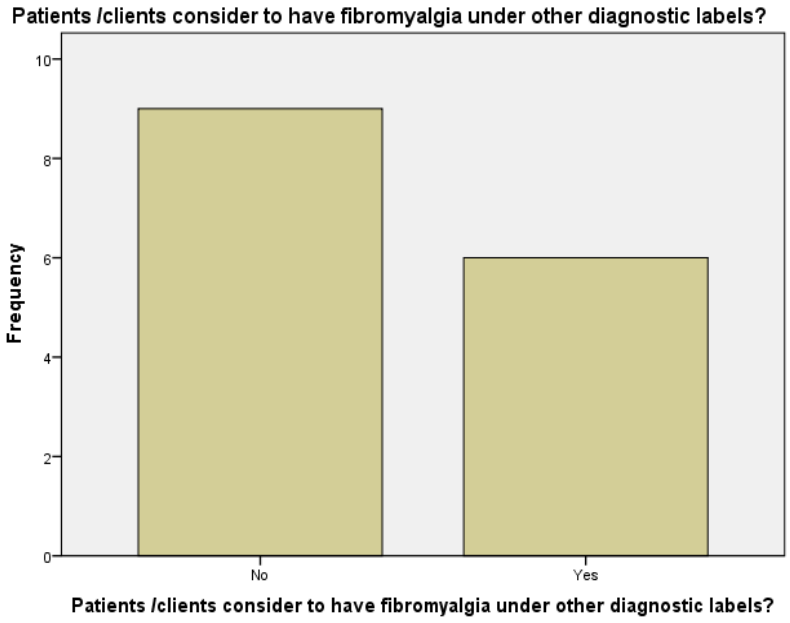

Figure 4.7.10: Patients considered by respondents to have fibromyalgia under other diagnostic labels

Table 4.7.12 shows that three respondents reported other diagnostic labels of chronic neck and low back pain, with the remainder of the respondents reporting osteoarthritis, rheumatoid arthritis, and muscle and joint pain. This data is also illustrated in Figure 4.7.11.

Table 4.7. 12: Patients seen under other diagnostic labels

Yes, other diagnostic labels					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Chronic neck & LBP	3	18.8	50.0	50.0
	Osteoarthritis	1	6.3	16.7	66.7
	Rheumatoid arthritis	1	6.3	16.7	83.3
	Muscle and joints pain	1	6.3	16.7	100.0
	Total	6	37.5	100.0	

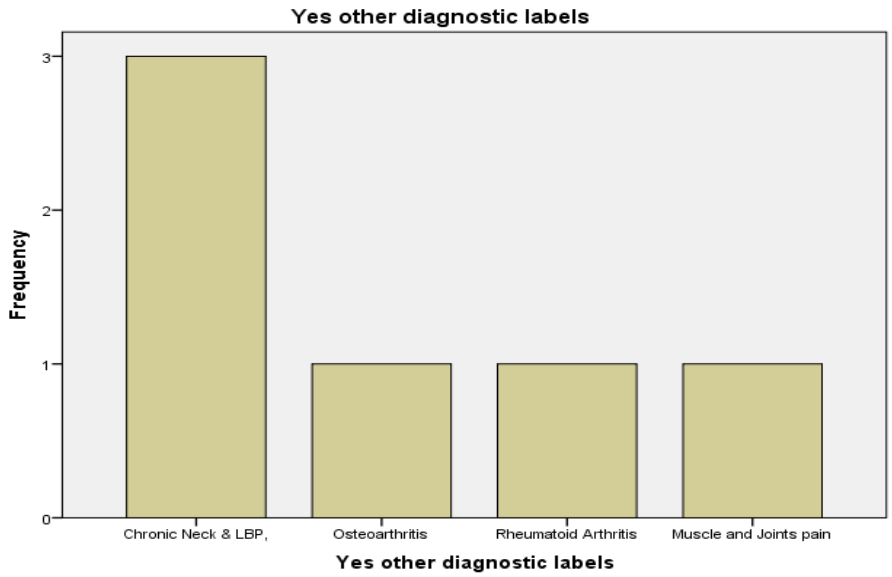

Figure 4.7. 11: Patients seen under other diagnostic labels

4.7.2.3 Symptoms and functional activity

The participants were asked about the extent to which patients generally show an increase in pain as a result of an increase in the level of physical activity. Table 4.7.13 shows that most of the respondents reported that their patients showed a moderate to severe increase in pain as a result of an increase in the level of physical activity.

Table 4.7.13: Extent to which patients showed an increase in pain as a result of an increase in the level of physical activity

Extent to which patients showed an increase in pain with an increase in the level of physical activity					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Mild	1	6.3	6.7	6.7
	Moderate	8	50.0	53.3	60.0
	Severe	6	37.5	40.0	100.0
	Total	15	93.8	100.0	

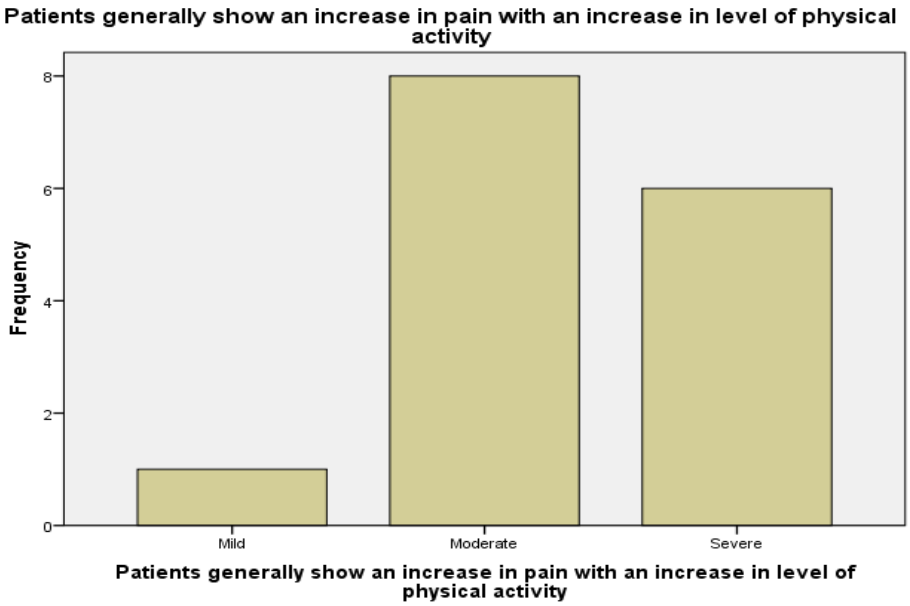

Figure 4.7. 12: Extent to which patients showed an increase in pain as a result of an increase in the level of physical activity

The respondents were also asked if patients used assisted equipment. Table 4.7.14 shows that the majority of respondents (66.7%) reported that their patients did not use assisted equipment.

Table 4.7.14: Patients using assisted equipment (e.g. walking aid)

Patients /clients use assisted equipment (e.g. walking aid)					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	2	12.5	13.3	13.3
	No	10	62.5	66.7	80.0
	Sometimes	3	18.8	20.0	100.0
	Total	15	93.8	100.0	

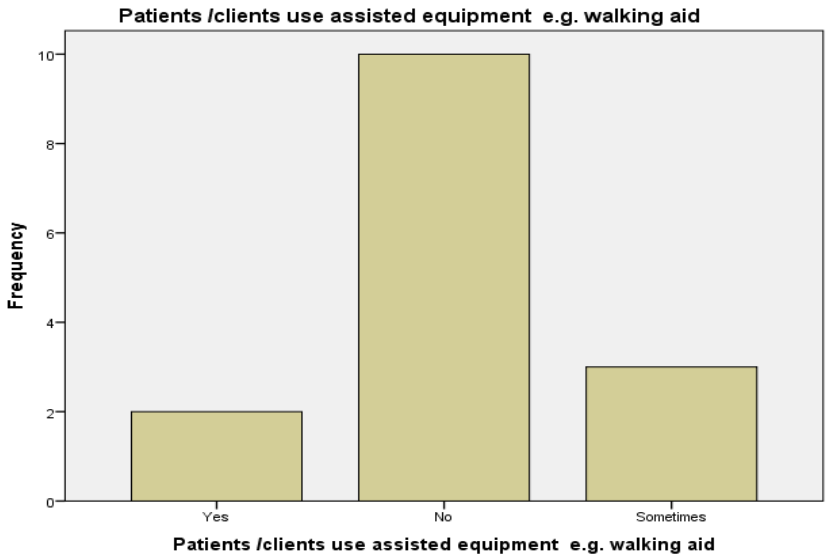

Figure 4.7.13: Patients using assisted equipment (e.g. walking aid)

The respondents were then asked regarding the aspects of the daily living that most affected their patients due to chronic pain. The respondents indicated that walking was the most affected aspect of daily living. The full set of results can be seen in Table 4.7.15 and Figure 4.7.14.

Table 4.7.15: Daily living aspects/activities most affected by fibromyalgia

Aspect/activity of patients/clients' daily living most affected by chronic widespread pain/fibromyalgia.					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Walking	9	56.3	60.0	60.0
	Running	3	18.8	20.0	80.0
	All of these	3	18.8	20.0	100.0
	Total	15	93.8	100.0	

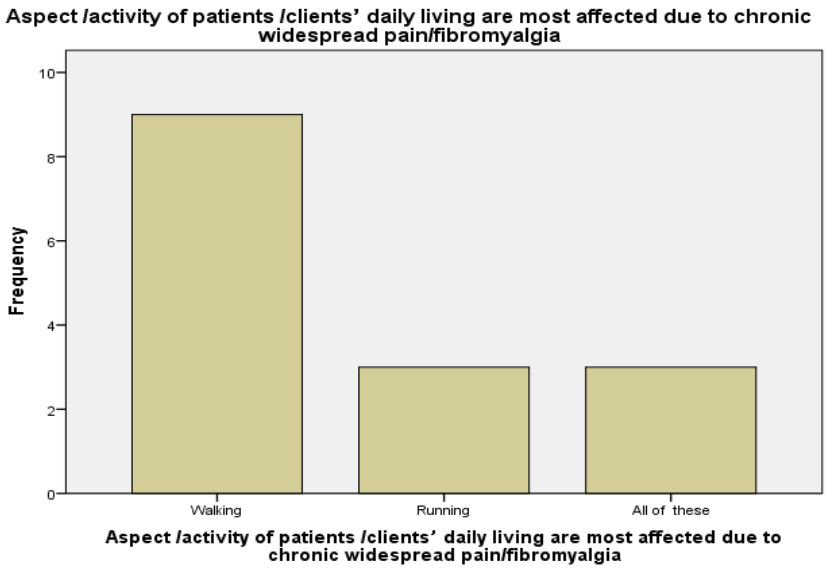

Figure 4.7. 14: Daily living aspects/activities most affected by fibromyalgia

4.7.2.4. Clinical features

The respondents were asked about the frequency of presentation of the various clinical features of fibromyalgia. Furthermore, they were asked to provide their responses using a Likert scale, where 1= always, 2= often, 3=sometimes, 4= seldom, and 5= never. The median value for each clinical feature is shown 4.7.16. It can be seen that most of the clinical features were rated as 'often', with the exception of loss of muscle power/endurance, and loss of joint range.

Table 4.7.16: Median responses for frequency of clinical features presented by patients

Clinical Feature	Median Response
Generalised pain	2
Localised pain	2
Tenderness on palpation	2
Excessive fatigue	2
Loss of muscle power/endurance	5
Loss of joint range	5
Stiffness	3
Loss of function	3
Psychological aspects	2
Peripheral circulatory	3.5
Others	4

The respondents were subsequently asked about which clinical symptom was most important to the patient. Table 4.7.17 and Figure 4.7.15 show that pain was the most important symptom, followed by fatigue and tiredness.

Table 4.7.17: Most important clinical features to fibromyalgia patients

Most important clinical symptoms/features to fibromyalgia patients					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Pain	7	43.8	63.6	63.6
	Fatigue, tiredness	4	25.0	36.4	100.0
	Total	11	68.8	100.0	
Total		15	100.0		

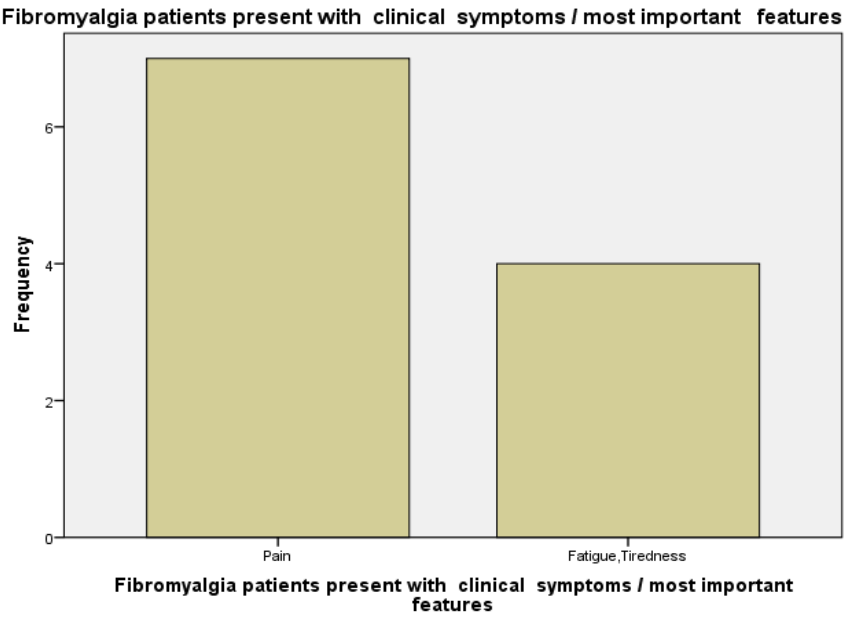

Figure 4.7. 15: Most important clinical features to fibromyalgia patients

4.7.2.5 Primary symptoms: pain assessment and measurement

Table 4.7.18 shows that the most frequent pain intensity measure used by the respondents was the verbal rating scale, followed by the numerical rating scale and the visual analogue scale. Three respondents did not routinely measure pain.

Table 4.7.18: Measurement methods of pain intensity

Methods used to measure the intensity of fibromyalgia patients' pain					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Numerical rating scale (e.g. 1-10)	4	25.0	26.7	26.7
	Verbal rating scales (e.g. severe, moderate)	5	31.3	33.3	60.0
	Visual analogue scale	3	18.8	20.0	80.0
	Do not routinely measure pain intensity	3	18.8	20.0	100.0
	Total	15	93.8	100.0	

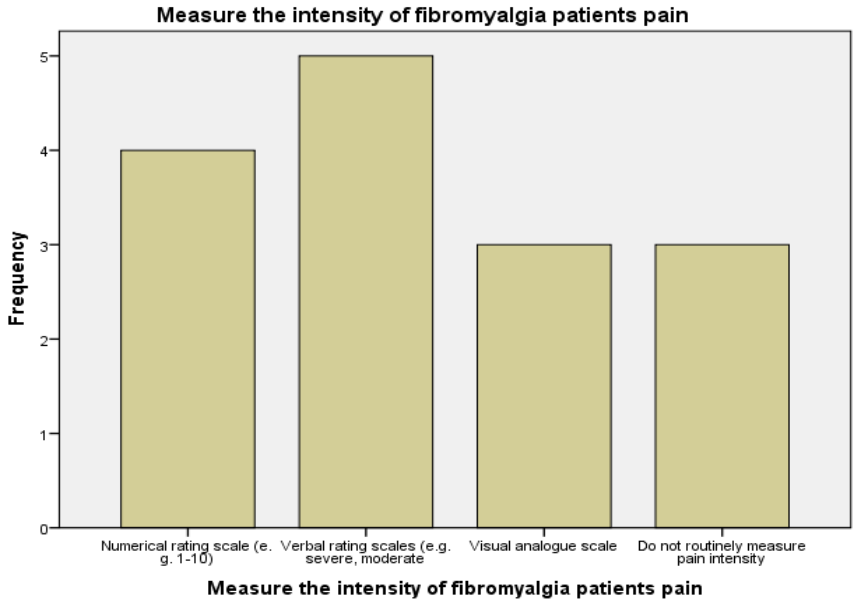

Figure 4.7.16: Measurement methods of pain intensity

4.7.2.6 Pharmacological approaches: medication prescribed to patients with fibromyalgia

The respondents were asked to state the frequency with which they prescribed medications in their practice. Six of the respondents (40%) reported that they used muscle relaxants, while another six respondents indicated that they did not prescribe any medications. Tramadol, amitryptiline, and combinations of medications were all seldom prescribed. The full set of data relating to this question is shown in Table 4.7.19 and illustrated in Figure 4.7.17.

Table 4.7. 19: Medications prescribed to patients with fibromyalgia

Medication prescribed to patients with fibromyalgia					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Tramadol	1	6.3	6.7	6.7
	Muscle relaxants	6	37.5	40.0	46.7
	Amitriptyline	1	6.3	6.7	53.3
	Combination	1	6.3	6.7	60.0
	Don't prescribe	6	37.5	40.0	100.0
	Total	15	93.8	100.0	

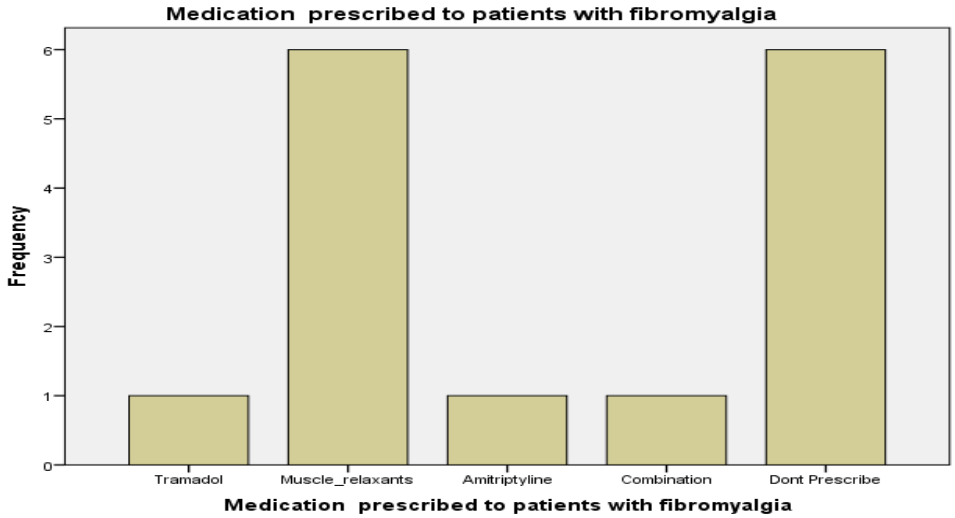

Figure 4.7. 17: Medication prescribed to patients with fibromyalgia

The respondents were then asked whether patients attended their practices without previous medications prescribed specifically for their symptoms. A total of 10 respondents stated that patients attended without medications, while five respondents stated that patients sometimes attended their clinics with a medication. Table 4.7.20 and Figure 4.7.18 present and illustrate the responses of the respondents, respectively.

Table 4.7.20: Patients presenting with medications specifically for their symptoms

Patients/clients have fibromyalgia, come without medications specifically for their symptoms					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	10	62.5	66.7	66.7
	Sometimes	5	31.3	33.3	100.0
	Total	15	93.8	100.0	

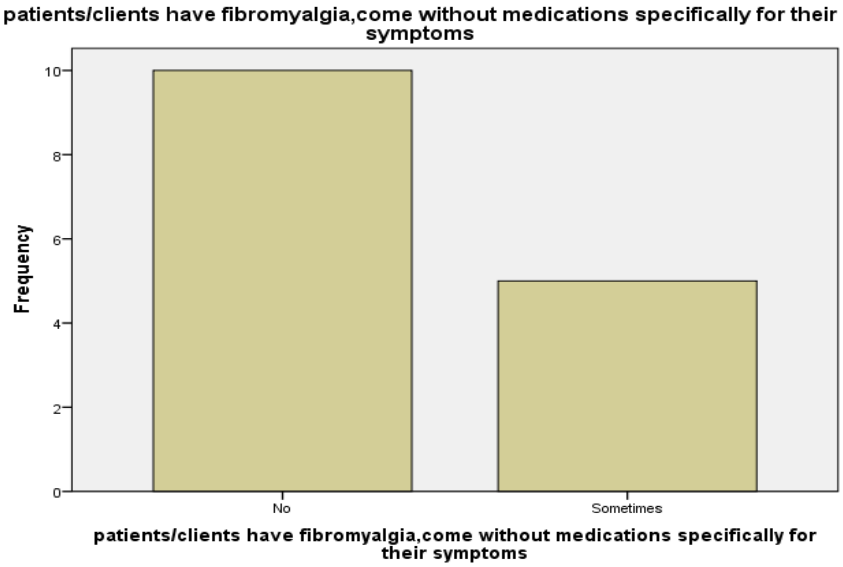

Figure 4.7.18: Patients presenting with medications specifically for their symptoms

4.7.2.7 Non-pharmacological interventional approaches

The frequencies of prescribing the use of various non-pharmacological interventional approaches were indicated on a Likert scale, where 1= always/almost always, 2= often, 3= sometimes, 4= seldom, 5= never/almost, and 6= not applicable. The median responses for these non-pharmacological interventional approaches are shown in Table 4.7.21 below.

Table 4.7.21: Median responses for the use of non-pharmacological interventional approaches

Intervention	Median response
Stretching exercise	2.5
Aerobic exercise	2
Graded exercise programme	3.5
Group exercise programme	4.5
Hydrotherapy	4.5
Postural re-education	2
Functional activity re-education	2
Cognitive behavioural therapy	5
Relaxation	3
Acupuncture	6
Ergonomic evaluation	6
TENS	6
Ultrasound	5.5
Manual therapy	3.5
Massage	3.5
Energy conservation	6

As can be seen from Table 4.7.21, the frequency of using non-pharmacological interventional approaches such as graded exercise programmes, manual therapy, and massage was ranked by a median response of 3.5. Group exercise and hydrotherapy were seldom used, while CBT was never used. Furthermore, some interventions were considered to not be applicable.

4.7 2.7 The use of a specific management programme for fibromyalgia

The respondents were asked if they had a specific management programme for fibromyalgia patients. The majority of the respondents had no specific management programme for fibromyalgia, while only two respondents (13.3%) had a management programme for chronic pain. The full data relating to this question is shown in Table 4.7.22 and illustrated in Figure 4.7.19.

Table 4.7. 22: Use of a specific management programme for fibromyalgia

Specific treatment/management programme for fibromyalgia patients					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	13	81.3	86.7	86.7
	Yes, for chronic pain patients in general	2	12.5	13.3	100.0
	Total	15	93.8	100.0	

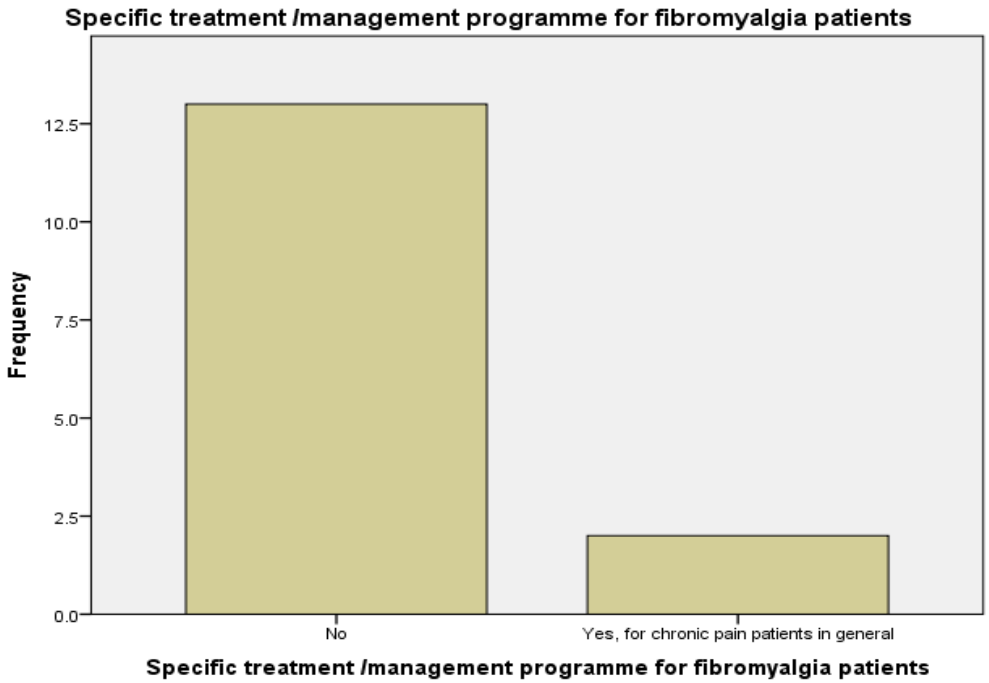

Figure 4.7.19 Use of a specific management programme for fibromyalgia

The respondent were then asked about the responsiveness of fibromyalgia patients to the interventional approaches. Table 4.7.23 shows that the majority of the respondents (n=14) reported that patients were 'moderately responsive'. The full set of results to this question is illustrated in Figure 4.7.20.

Table 4.7.23: Views of the respondents on the responsivity of fibromyalgia patients to interventional approaches

Responsiveness of fibromyalgia patients to interventional approaches					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very responsive	1	6.3	6.7	6.7
	Moderately responsive	14	87.5	93.3	100.0
	Total	15	93.8	100.0	

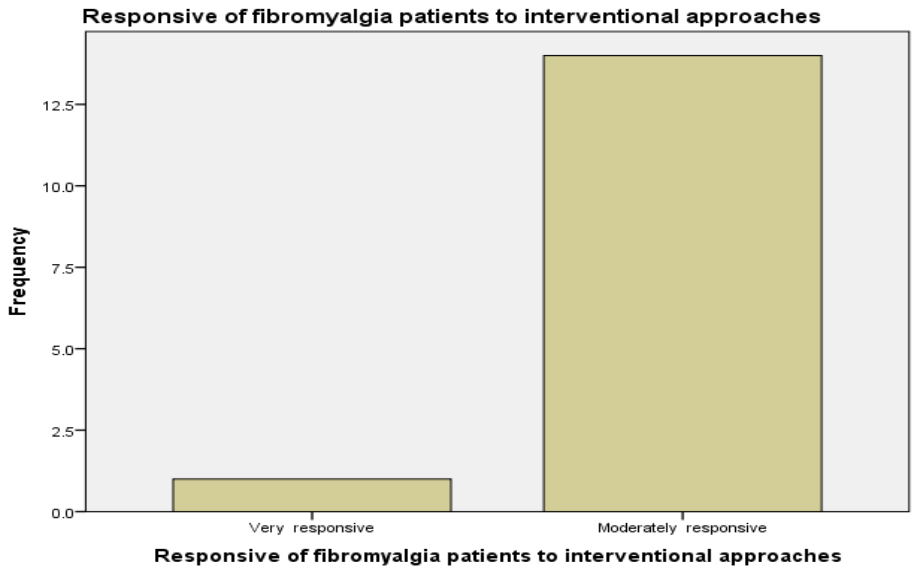

Figure 4.7.20: Views of the respondents on the responsivity of fibromyalgia patients to interventional approaches

The respondents were also asked regarding their aims and what they hoped to achieve from a rehabilitation programme for fibromyalgia patients. Table 4.7.24 shows that he majority of the respondents reported that their aim was to improve physical functions.

Table 4.7. 24: Aims of a fibromyalgia rehabilitation programme

Achieve from a fibromyalgia Rehabilitation Programme					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Improve physical function	12	75.0	100.0	100.0
Missing	.00	3	18.8		
Total		15	100.0		

4.7.2.9 Clinicians' attitudes and opinions

The respondents were asked to state their opinions regarding a number of statement relating to FMS patients (shown in Table 4.7.25), using Likert scales, where 1= strongly agree, 2= agree, 3= neither, 4= disagree, and 5= strongly disagree =5. The median responses for the statements are shown in Table 4.7.25. The respondents agreed that FMS patients had considerable psychological overlay, and that the FMS diagnosis was made once all other diagnoses had been tried and rejected. They also agreed that patients were well informed on their condition, and that treatment must not aggravate pain. On the other hand, the respondents were undecided regarding whether patients were able to self-manage their condition.

Table 4.7. 25: Median responses to attitudinal questions

Statement about FMS patients	Median response
Patients have considerable psychological overlay	2
Treatment must not aggravate patients' pain	2
Restoring function is more important than treating pain	3
The diagnosis is made once all other diagnoses have been tried and rejected	2
Patients are generally well informed on their condition	2
Patients are able to self-manage their condition	3

The subsequent section present some descriptive comparisons between the responses of the UK and Libyan healthcare professionals in each of the key areas of the survey regarding diagnosis, referral, management and attitudes and opinions.

4.7.2.10. Descriptive comparison between the two groups (UK and Libyan HCPs) regarding the number of participants in this study.

The total of UK potential sample were 600 participants and the number of UK respondents were 53, however, the total of Libyan sample were 25 participants and respondents' number were 15. Table 4.7.26

Table 4.7.26 the number of participants/respondents

Samples	Total UK sample	Total Libyan sample
Participations Number	600	25
Respondents	53	15

4.7.2.11 Descriptive comparison between the two groups (UK and Libyan HCPs) regarding the number of patients HCPs see each month.

Forty three percent of UK-based respondents indicated that they saw a new patient each month, compared with 73.3% for the Libyan sample. Table 4.7.1 shows a breakdown of the numbers of new patients seen each month by the two groups.

Table 4.7.27: Number of new patients seen each month (UK and Libyan samples)

New patients seen each month	UK sample	Libyan sample
1-4 patients per month	34%	73.3%
5-9 patients per month	36%	20%
10-15 patients per month	30%	6.7%

4.7.2.12 Descriptive comparison between the two groups on referral sources

The majority of UK respondents reported that patients were often referred by GPs (81.3%) and rheumatologists (84.2%), compared with the Libyan respondents who reported a smaller proportion of patients referred by GPs (45.5%), and a higher proportion by Orthopaedics (66.7%). See table 4.7.28

Table 4.7.28: Comparison between UK and Libyan HCPs' responses on patients' referral sources

Patients referred under	UK sample	Libyan sample
GPs	81.3% often	45.5% often
Rheumatologist	88.2% often	50% often
Orthopaedics	23.3% sometimes	66.7% sometimes

4.7.2.13 Comparison between the two groups on specific management programmes (SMP) for FM see table 4.7.29

Table 4.7.29: Comparison between UK and Libyan respondents' answers on specific management programmes

Treatment received	UK sample		Libyan sample	
Specific management programme (SMP) for FM	No	Yes	No	Yes
	26%	12%	86.7%	0.0%
SMP for chronic pain in general	62%		13.3%	

4.7.2.14 Comparison between UK and Libyan respondents' answers on pharmacological management programmes.

Table 4.7.30 Comparison between UK and Libyan respondents' answers on pharmacological management programmes.

Medications prescribed to patients with fibromyalgia		
	UK sample	Libyan sample
Amitriptyline	2.0%	6.7%
Combination	85.7%	40%
Tramadol	-	6.7%
Muscle relaxants	-	40%
Do not Prescribe	12.2%	6.7%

4.7.2.15: Descriptive comparison of the attitudes and opinions of UK and Libyan respondents.

Table 4.7.31: Descriptive comparison of the attitudes and opinions of UK and Libyan respondents'

	UK sample Median Response	Percentages	Libyan sample Median Response	Percentages
Statement about FMS patients				
Patients have considerable psychological overlay	2	49.0%	2	80%
Treatment must not aggravate patients' pain	4	52%	4	64.3%
Restoring function is more important than treating pain	2	46%	2	35.7%
The diagnosis is made once all others diagnoses have been tried and rejected	2	38%	2	7.7%
Patients are generally well informed on their condition	4	26%	4	38%
Patients are able to self-manage their condition	3	33.3%	3	38.%

4.8 Discussion

The study described in this chapter aimed to explore current practice for fibromyalgia in the UK and Libya. This included exploring approaches to the assessment and managements of FMS regionally, and between the UK and Libya, as well as investigating the attitudes and opinions of HCPs regarding the condition and responsiveness to interventions used in clinical practice, and the availability of such interventions. The responses showed regional variability of current practice in both diagnostic and management approaches. This study has developed and expanded a previous UK based survey study of physiotherapists and occupational therapists (Sim and Adams 2003), which investigated approaches to fibromyalgia. This was achieved

by extending the scope of research to include other professional groups involved in the management of fibromyalgia, exploring the use of pharmacological management, as well as exploring the assessment and management of fibromyalgia in Libya.

It was valuable to conduct the parallel survey on chronic widespread pain in Libya in order to consider different healthcare professionals practice, gain a broad view of the differences in approaches to the management of chronic widespread pain, and highlight the issues surrounding incorporation of intervention approaches and availability. Responses from both the UK and Libya were consistent with the diagnostic criteria for fibromyalgia set by the American College of Rheumatology (Giordano et al., 1999).

To follow, the findings of this study are discussed in terms of the diagnosis processes used in practice, the interventions used by healthcare professionals, and their views of standardised approaches, and how the results may develop the future of assessment and management of fibromyalgia and influence directions for future research.

4.8.1 Diagnosis and referral

The definition of fibromyalgia used in the study was based on the 1990 diagnostic criteria produced by the American College of Rheumatology, which requires the presence of chronic widespread pain for three months or longer, as well as 11 of 18 specific tender points (TP) sites. The results from the survey showed that the respondents reported a high percentage of patients closely fitting the description (90%), with a further 3.8% of patients who more or less fitted the description. Although the ACR criteria has been approved by the ACR board, it is often not formally adopted as a screening tool for FMS-like disorders (Smythe, 2011, Thompson, 2010), as diagnostic practice is often variable with inconsistent application of the criteria (Wolfe et al., 2013). It was therefore helpful to have included the criteria in the questionnaire.

Differential diagnosis is common, with patients being referred under different diagnoses. Consistent with the findings of other studies, the results of our study showed that a high proportion of patients who fitted the diagnostic criteria of FMS were diagnosed differentially with other conditions. As a result of differential

diagnosis and different routes of referral, it was found that patients were both diagnosed and referred by different specialties.

The finding that the most common referral source were GPs and rheumatologists is similar to the findings of Choy et al. (2010) and Able. et al. (2016), suggesting that rheumatologists were more likely to use a diagnostic label of fibromyalgia, and that patients with these symptoms were more likely to be referred to rheumatologists rather than any other specialty. In addition, the study by Choy et al. (2010) identified a high level of referral from GPs, which is comparable to the findings of our study. The results of our study also concur with current literature regarding the self-reported ability of physicians to diagnose fibromyalgia. These findings contrast with those of

(Hayes et al., 2010) who found that 25% reported doubt in diagnosing fibromyalgia. However, this may have reflected the variability of patients with symptoms of pain and fatigue. This figure was reduced for specialists, who presumably have greater training and awareness in recognising symptoms and applying diagnostic criteria. Given that the sample in the current study was recruited from the British Pain Society, it was largely, by definition, a sample of specialists, who had a specific interest in pain management.

Choy et al. (2010) found that general practitioners reported deficiencies in diagnosing and treating FMS more frequently than specialists did. As patients first attend primary care, where they may either receive a diagnosis or be referred onwards to a specialist for diagnosis and treatment, a future direction of research would be to investigate the assessment, diagnosis and management within the primary care setting. It is important to note that fibromyalgia is often a co-morbid condition, which may also obscure its diagnosis (Wolfe et al., 2011). This fact was clearly observed from the findings of our study, where clinicians agreed that fibromyalgia often manifested as a co-morbid condition. Furthermore, similar to other studies, it was found that FMS coexisted with a diagnosis of another somatic disease, such as inflammatory arthritis, osteoarthritis, or a mental disorder such as depression (Ablin et al., 2013, Fitzcharles et al., 2013c, Eich et al., 2012). The results also showed that rheumatoid arthritis was the most frequent co-morbid condition, consistent with the results of (Martin et al., 2014) who found that participants who completed clinician data were reported that to have another

diagnosis causing pain, such as rheumatoid arthritis, osteoarthritis, degenerative disc disease (DDD), neuropathy, and chronic pain. The presence of comorbid disorders might be an essential factor that can be used to help the diagnosis of FMS. Furthermore, the co-morbidity may influence treatment approaches and options, though this was not formally investigated in our study.

A population-based study using the 31-point self-report questionnaire found that 17% of 845 patients with osteoarthritis, 21% of 5210 with rheumatoid arthritis, and 37% of 439 with systemic lupus erythematosus, fulfilled the 2010 ACR criteria for fibromyalgia (Wolfe et al., 2011), illustrating that difficulties in diagnosis may be related to such comorbidity. However, it could also be argued that fibromyalgia is not a distinct clinical entity, but rather a response shown by many patients who exhibit a chronic condition. The results of our study also show that the UK respondents reported that (53.6%), of patients attended their clinics under labels of chronic neck and back pain, and 21.4% of patients under labels of chronic fatigue. The finding from Libya was differed a bit and the diagnosis is not formally used in Libya though this study provides the first evidence that clinicians do recognise the condition .

(Kim et al., 2012) highlighted that physicians who referred patients to a rheumatologist for suspected FMS missed a diagnosis of inflammatory or degenerative arthritis, or soft tissue rheumatism in 45% of patient conditions. However, FMS may also be over diagnosed, which carries the risk of failing to identify and treat conditions that are highly amenable to therapy (Fitzcharles and Boulos, 2003). The results of our study show that the respondents reported GPs and rheumatologists as the most frequent source of patients referral, where more than half of the patients attending their clinics were diagnosed with FMS.

4.8.2 Symptoms and clinical features

Our results agreed with the clinical features identified in the ACR diagnostic criteria, and reported by previous studies, in that symptoms often include a diverse series of other conditions, such as physical and mental fatigue, disrupted or non-restorative sleep, headache, irritable bowel, psychiatric disorders, cognitive impairment, and other functional complaints (Schmidt et al., 2011, Abeles et al., 2007). Furthermore, our results are congruent with a previous Delphi study building consensus via

questionnaires and systematic opinion feedback, which involved 23 clinicians with expertise in FMS, and 100 patients with FMS as defined by ACR criteria. Both panels consistently ranked pain highest. Fatigue, impact on sleep, health-related quality of life, comorbid depression, and cognitive difficulty were also ranked highly (Mease et al., 2008). Our results regarding the frequency of occurrence of clinical features show that pain was generally ranked highest by healthcare professionals, followed by fatigue. Loss of function was less often reported, in contrast to a Delphi study by Mease et al. (2008), who found that patients, but not clinicians, ranked stiffness highly. However, this is consistent with the results of the qualitative study in Chapter 3 of patients' perspectives, where joint stiffness was highly ranked among people with fibromyalgia, and was reported to affect the ability to perform functional activities.

The symptoms of fibromyalgia are often found to impact all functional and daily living activities. This was also supported by the results of the Fibromyalgia Impact Questionnaire (FIQ) presented in the previous chapter.

The results of our study also showed that patients often had clinical features such as localised pain, loss of muscle power, loss of function, stiffness, and psychological issues. All of these features received high rankings from the respondents. Moreover, the study found that pain, functional disability, and fatigue severity were ranked as the top three categories by the highest proportion of physicians when evaluating FMS severity, which concurs with the findings of the study by Silverman et al. (2010).

However, comorbidities increase the complexity of patients' symptoms, and are likely to impact on the rapidity of diagnosis. This means that patients may require more consultation time, and that collaboration with HCPs and specialists may be essential to produce an optimal diagnosis and management approach (Arnold et al., 2011, Davis et al., 2011, Ahmad and Tagoe, 2014).

4.8.3 Pain assessment and measurement

In our study, the majority of HCPs (50%) reported that they did not use a standardised assessment instrument in UK practice and showed that Libya HCPs used assessment tools more than UK. The most frequently used assessment instrument was the numerical rating scale (1-10), which was used by 39.6% used of HCPs, followed by

the verbal rating scale (6.3%), and the visual analogue scale (4.2%). Our results also show that the Hospital Anxiety and Desperation Score (HADS) was used by 31.8% of HCPs, and the Brief Pain Inventory (BPI) was used by 45.5% of HCPs, as assessment tools in the UK. However, despite the German guidelines which recommend the use of the fibromyalgia survey questionnaire to assess FMS-like symptoms and severity (Hauser et al., 2012a), and the fact that the FIQ is most often used as an outcome measure in many studies of FMS, they appear to be used relatively rarely in clinical practice.

4.8.4. Pharmacological approaches: Medication prescribed to patients with fibromyalgia

A recent study on pharmacological approaches found that amitriptyline had effects on FMS symptoms of pain, sleep disturbance, fatigue, affective symptoms, functional deficit and cognitive impairment, whereas non-pharmacological therapies routinely had multidimensional targets (Perrot and Russell., 2014). These findings differ from our study's, in that combinations of medications were found to be prescribed for patients by the majority of the respondents (85.7%), whereas amitriptyline was less often prescribed, presumably due to its side effects. However, our results concur with the recommendations regarding pharmacological management of symptoms of fibromyalgia (Knight. et al., 2013 , Häusera et al., 2010).

Our results also demonstrated the variety of medications used for FMS patients in UK, 2.0% prescribed amitriptyline where, for instance 12.2% of HCPs reported that they do not prescribe any medications for FMS patients. However, in Libya, 40 % of HCPs prescribed muscle relaxants, 6.7% prescribed amitriptyline, and 6.7% prescribed tramadol, where 40 % of HCPs do not prescribe any medications. Interesting comparisons can be between our findings and those of the study by Roskell. et al. (2011), who found that tramadol combined with paracetamol was more likely to have 30% improvement in pain, compared with either medication alone. The variability of practice, and the differences found between the results of our study and the literature may be explained by the study being conducted in the UK, and most of the published literature being based in the USA, where healthcare practices differ significantly. In fact, the German guideline favoured non-pharmacological treatment, and advocated timely limited medications only in moderate and sever forms of FMS pain (Eich et

al., 2012 , Sommer et al., 2012), which appear to be the approaches used by the clinicians in our study. The EULAR 2016 guidelines highlighted the change in attitudes regarding intervention approaches to FMS, but offered varying recommendations with regards to the use of pharmacological interventions such as amitriptyline, pregabalin and duloxetine, which are commonly used for FMS (Macfarlane et al., 2017). Given the fact that there is no single treatment currently targeting all symptoms of FMS, multidisciplinary management is required, using a comprehensive multifaceted medications plan that integrates pharmacotherapy, cognitive behavioural therapy, patient education, lifestyle changes (e.g. stress reduction, sleep hygiene), physical therapy, and exercise.

4.8.5 Non-pharmacological interventional approaches

(Carville et al., 2008b) reported that exercise therapy had the greatest evidence base, and featured as their highest recommendation for FMS management. Our results also showed that the respondents most often used active interventions, such as exercise. In particular, graded exercise programmes and stretching exercises were most frequently used, followed by aerobic exercises. These results show similarities to previous studies, where aerobic exercises were found to reduce fibromyalgia symptoms, and improve physical capacity, although such exercises need to be slow and build up gradually, in the form of a graded exercise programme (Fitzcharles et al., 2013b, Busch et al., 2007). Our study also showed that the respondents sometimes used hydrotherapy for FMS patients. A recent study reported that pool/water therapy showed broad efficacy across all domains of FMS (Perrot and Russell., 2014). Furthermore, the study highlighted that when a facility is available, pool exercises can be quite economical. These findings are consistent with the reports from patients in Chapter 3, where the lack of service availability for this intervention was highlighted by fibromyalgia patients in north east of UK, and which they would have liked to have available. In line with previous studies by (Miro et al., 2011, Schmidt et al., 2011, Ang et al., 2010, Hsu et al., 2010), who demonstrated that CBT was effective for pain, sleep disturbance, cognitive and functional impairment, CBT was frequently used by the respondents in our study, with 40% of the respondents using CBT in their practice. This may have been due to the particular sample of respondents in this survey, who were recruited from the British Pain Society. It was interesting to note that although Libyan clinicians

acknowledged the role of psychological factors in FMS, as CBT is not routinely used in Libya, it was not part of their practice.

The respondents less often used specific techniques, though acupuncture was identified as an intervention that was sometimes used. This is unsurprising as the literature on acupuncture for FMS is equivocal, with some studies and patients suggesting no benefit, and others, such as Deare et al. (2013), demonstrating that acupuncture, added to standard therapy, resulted in a 30% improvement in pain. Forty percent of the respondents of this study reported that they did not prescribe specific treatment management programme for FMS, while 50.8% reported that they prescribed treatment for chronic pain in general. Only six respondents reported the prescription of treatment specifically for FMS.

4.8.6 Clinicians' attitudes and opinions

Both UK and Libyan respondents considered patients with FMS to have considerable psychological overlay. The UK respondents agreed that restoring function is more important than treating pain, though the Libyan respondents were undecided. Furthermore, the respondents agreed that a fibromyalgia diagnosis was made once all others diagnoses have been tried and rejected, which is consistent with the findings of previous research studies (Able. et al., 2016, Choy et al., 2010), and is consistent with the findings of our study regarding comorbid symptoms, differential diagnosis, and the variety of diagnostic labels used.

4.9.Summary of key findings of the survey

- **Diagnosis and differential diagnosis**: About half of patients already had a diagnosis of fibromyalgia, though many fitted the description of FMS provided, but were referred under different diagnostic labels. This was the case for both the UK and Libya. The most common differential diagnostic label was chronic neck and back pain.
- **Clinical features**: Pain was the primary presenting symptom, followed by fatigue.
- **Referral sources**: Patients were most often referred by GPs and rheumatologists

- **Physical and functional activity**: Physical activity often resulted in a moderate to severe increase in pain. All daily activities were affected, particularly walking.
- **Assessment**: Many UK respondents did not routinely assess pain and it was assessed more often in Libya. ? For those who assessed pain, the most common instruments used were numerical, verbal, and visual analogue scales. The BPI was sometimes used, but no respondent reported using the FIQ.
- **Pharmacological management**: There were differences in pharmacological management between the UK and Libya, with combinations of drugs being commonly used in the UK, and muscle relaxants more frequently prescribed in Libya. Many of the respondents were not medical practitioners, and therefore did not prescribe any medications.
- **Non-pharmacological management**: The most frequently used non-pharmacological approaches were active approaches, such as graded exercise programmes and other forms of exercise. CBT was used in the UK, but was not used in Libya, where manual therapy was more often used. Manual and massage therapy was not used by the UK respondents.
- **Aims of rehabilitation**: The respondents in both countries viewed the primary aims of rehabilitation to be to improve function and to cope with pain.
- **Attitudes and opinions**: The respondents in both countries had similar attitudes and opinions. For example, both considered that there was a considerable psychological overlay in the condition, but were undecided about whether patients could self-manage their condition.

4.10. Conclusions

The study presented in this chapter showed that there were no standardized assessment or management programmes during the journey of FMS diagnosis, and that specialities are needed for better symptom management and intervention approaches. Furthermore, the study highlighted that FMS shared symptoms with other co-morbid conditions, that patients were labelled under a variety of diagnostic labels, such as chronic neck and back pain, chronic fatigue and IBS, and that a diagnosis was made once other diagnoses have been tried and rejected. In addition, it was found that physical and daily living activities were affected as a result of pain severity, and that

patients with fibromyalgia had a considerable psychological overly. Pharmacological approaches that were routinely prescribed to fibromyalgia patients were reported to include muscle relaxants and painkillers, which are medications that are prescribed for chronic pain in general. Furthermore, physiotherapy and CBT were prescribed to reduce pain and increase physical function, while no medications were prescribed specifically for FM symptoms.

Chapter Five: General Discussion, And Conclusions

5.1 Introduction

This section provides an overview of the main study findings and the original contribution of the thesis is also discussed.

5.2 Aims of the Study

The thesis sought to answer the following research questions

4. What are views and experiences of service users regarding their condition the impact upon their lives and how these influence their health care seeking behaviours and experiences of interventions?
5. What are the range of fibromyalgia interventions and the diagnostic/ assessment process they have experienced/sought?
6. What is current practice regarding fibromyalgia in the UK and what is current practice in Libya.

The specific aims of the study were as follows:

- To explore participants' views and experiences regarding issues that impact upon their condition.
- To explore service users' and service providers' views regarding the experience and management of fibromyalgia.
- To explore the extent to which emotional issues impact upon the experience of fibromyalgia.
- To describe current practice for FMS in the UK and Libya
- To consider similarities and differences in approaches to the management of FMS between the UK and Libya
- To explore service users' and service providers' attitudes and opinions regarding the nature of fibromyalgia and the interventional approaches used.

5.3 Original Contribution to Knowledge

- This study is the first to explore health professionals' views of the diagnosis and management of fibromyalgia in a Middle Eastern country. Such data is currently lacking.
- This study is also the first to explore and synthesis of the views of service users and service providers in the UK.

- The study provides an in depth exploration of the various dimensions of the experience of fibromyalgia from a service user's perspective.
- The study provides a description of practice of health care professionals from different backgrounds in the UK regarding fibromyalgia pharmacologically and non- pharmacologically.

5.4 Synthesis of Main Findings.

The synthesis of findings is presented in the following sections relating to diagnosis and the journey to diagnosis, the clinical features, variability and unpredictability of symptoms, the experience of available interventions and management of symptoms and emotional experience and expression.

5.4.1 Diagnosis and the Journey to Diagnosis.

Participants referred to the variety of examinations and tests they had undergone in order to reach a diagnosis. There is yet no definitive test for fibromyalgia and the diagnosis is made upon the presenting symptoms in the absence of any other organic finding from objective tests. This has of course raised controversy as to whether fibromyalgia exists as a distinct clinical entity and as such is referred to as a syndrome. Many sufferers reached their diagnosis by either a GP or a consultant and the time taken to reach a diagnosis was variable and could take a number of years. This was also confounded by many co-morbidities and medications taken by participants.

Patients questioned why the referral process should take such a long time to see a consultant, though perhaps this may have been due to a lack of clarity about which specialist to whom the patient should be referred and indeed, if there are specialist facilities available within the various regions. The reasons for referral or non-referral was not specifically explored in this study and is an area that could be developed in future research. The difficulty of diagnosis and the effect of the label of 'fibromyalgia' was not always perceived to be helpful. Comparable to the reports of participants in the exploratory interviews, a range of diagnostic tests were noted by practitioners who also considered a range of differential diagnoses. It was particularly interesting to note that whilst fibromyalgia is not a diagnosis that is used in Libya, the health care professionals, who were both medical doctors and physiotherapists….., recognised the syndrome from the definition provided on the questionnaire and also provided the same differential diagnoses to the UK clinicians. Although the syndrome is well

documented in Western society, it appears that although the syndrome is recognised in the Libya, it is not diagnosed specifically as fibromyalgia. Clinical features were reported consistently between clinicians and patients. It appeared that it was the variability and unpredictability of symptoms that proved difficult to manage.

5.4.2 Variability and Unpredictability of Symptoms

Clinical features as recognised by the ACR diagnostic criteria were consistent across the participants and also the UK and Libyan clinicians. The primary presenting symptom of pain was closely followed by fatigue, however participants reported that the fatigue and unrefreshing sleep affected every aspect of their lives, mood and functioning. This appeared to be the most difficult symptom to manage both by participants and clinicians. The most distressing characteristics was the unpredictability of the symptoms and their fluctuation on a daily basis. Many participants struggled with the lack of control over their symptoms and felt that they could manage their pain if they felt more in control of exacerbations and flare ups and could find an approach that appeared to work consistently.

It appears that there is not only variability of the experience of the symptoms and ability to function between patients but also variability within patients.

5.4.3 Experience of Available Interventions and Management of Symptoms

Many participants had tried a range of interventions with varying degrees of success which included a range of medications and sometimes in conjunction with non-pharmacological interventions. It was interesting to note that whilst practitioners reported using active interventions in their practiced, such as exercise and CBT, patients had accessed other interventions privately such as chiropractic and acupuncture. This concords with findings from previous studies of seeking CAM therapies for fibromyalgia (Hardy-Pickering and Adams 2007). There was variability amongst participants which is consistent with varying presentations of fibromyalgia, varying chronicity and co-morbidity and differing experiences of referral with some participating in pain management programmes. Findings were consistent with the heterogeneity of the condition. Practitioners offered a range of interventions and some had specific fibromyalgia programmes, though more often they had chronic pain management programmes. This was also the case in Libya, where fibromyalgia is

recognised as a chronic pain syndrome but not given a specific label or diagnosis. Although there is evidence of effectiveness for cognitive- behavioural therapy, many respondents did not find this helpful. This was perhaps surprising as the basic tenet is to help people to cope with their symptoms and daily activities more effectively and focus upon managing their symptoms, rather than finding a 'cure'. It is also surprising as this is the basic tenet of pain management programmes and it is suggested that perhaps participants were unaware of the interventions that fall under the aegis of CBT and considered this aspect consisted of a psychological input for something that was ' all in the head' and thus felt they were not believed. The interventions used and the treatment priorities were largely similar to the earlier study conducted by (Sim and Adams, 2003b).

Current guidelines recommend exercise as a primary component in any management programme. It is however, interesting to note that respondents found that physical activity and walking increased their pain and thus they were reluctant to engage in exercise. This emphasises the need for patient education and support which was also identified in the qualitative study.

5.4.4 Emotional Experience and Expression

Participants often reported emotional feelings associated with their condition. Most of these were reactive to the pain and fatigue and lack of ability to function. They described feelings of fear, related to anxiety, and of sadness, related to depression. These are well documented in the literature. However, they often described feelings of frustration and annoyance. These are more characteristic of anger. Some used the word 'angry' though it is an emotion that is not well documented or discussed in the literature.

Participants exhibited high levels of alexithymia and so they had difficulty in recognising, explaining and differentiating their emotions. This would affect their cognitions and response to interventions and also their feelings of being understood by clinicians, which was an important theme within the interviews. Clinicians in the UK and Libya both agreed that there was a high level of psychological involvement in fibromyalgia. Participants on the other hand often did not acknowledge the extent of psychological involvement and resented being referred to a psychologist or perceived the implication that their condition was not 'real.' However, some participants

understood the purpose of psychological intervention, either as cognitive-behaviour therapy or as part of a pain management programme was to help them live better with their condition and find ways of coping on a daily basis with the symptoms and the fluctuation of symptoms. These findings support the theory of a stress-induced disruption of the HPA axis (McBeth et al 2005:McVeigh et al 2007), due to exposure to prolonged stressful symptoms, with consequent amplified pain perception. High levels of fibromyalgia impact and alexithymia corroborate the qualitative findings. This high level of alexithymia indicates an inability to identify accurately their own feelings and thus limits their ability to regulate their emotions and also verbal communications of psychological distress, which impacts upon depression and anxiety, perceived disability and relationships with others, including health professionals.

5.4.5 Lack of Understanding

Lack of understanding was a recurring theme from the interviews with participants who felt that they were not understood by either health professionals, their families or the general public. Some patients reported having lost their jobs because of the disability and lack of understanding in the workplace if they were honest about the condition and told the employer that they have Fibromyalgia and felt there was a stigma attached to the condition. They also felt they could not get a job because of the FMS and this affected their daily life, resulting in feelings of felt frustration in living with a long-term condition, often returning to doctors seeking further assessment for their pain. However, with no definitive results from investigational tests, they felt there were few options available for management. The feeling of a lack of understanding related to the 'invisibility' of their condition and also its variability and unpredictability and also the lack of research that has been conducted on the condition in the UK and an absence of definitive clinical guidelines upon which to base interventional approaches. It was an interesting paradox that health professionals, in contrast, did not think patients were well informed about their condition. This is possibly due to the way that patients accessed information, which tended to be from a support group or from the internet. As such, much information is unsolicited and patients are often not able to critically evaluate claims made on the internet or in the popular press. Patients reported not being consulted regarding their options and preferences for management and control of symptoms by health professionals. There

is a need for advice and support from a trained health professional as a point of contact, perhaps at regular follow-ups after assessment and/or intervention with an approach that involves shared decision making with the patient.

5.4.6 Role of Self-Management

Self –management is a complex phenomenon that can be difficult to define and thus, there is no single understanding of individuals self –management (Kendall et al., 2011). A multi-dimensional process of self-manage of pain individuals determined pain being an active in their treatment, engaged in the personal development of skills and being aware of their own responses to symptoms (Stewart et al., 2014) because of lack of understanding of the illness people with FMS were struggled to manage their condition symptoms. Further research on what is meant by self-management by clinicians and also how patients can be supported to self-manage is warranted.

5.4.7 Conclusion

Fibromyalgia is a difficult and distressing condition and its prevalence appears to be increasing in the Western world. It is also reported in the Middle East, though there is not a specific diagnostic label of fibromyalgia for this chronic pain condition. Sufferers report a range of symptoms and experience and, as the diagnosis is based upon symptoms, may experience a long journey to obtaining a diagnosis. Variability within and between patients results in a range of approaches with little standardisation and considerable variability between regions. There are no specific guidelines for management, though recommendations and current evidence suggests a multicomponent approach. Emotional and psychological factors appear to play an important mediating role and this should be explored in management practices. There is a need for standardisation of services and service availability in the UK and more support and guidance for people with fibromyalgia in order to manage their condition

Chapter Six: Future Research and Recommendations

1.1 Introduction

This section provides the implications of the study and discusses the limitations and direction for future research, and finally reflections upon the process of conducting the study.

6.2 Future Research

This is the first study that has documented fibromyalgia in the Middle East, specifically in Libya, where the diagnosis is not used. However, the clinicians recognised the signs and symptoms and the syndrome and treated it accordingly, and in a similar manner to that described to their UK counterparts with the exception of psychological involvement. There is much scope for research into how fibromyalgia is recognised, diagnosed and managed in the Middle East. This data is hitherto lacking. It would be difficult to conduct a national survey in Libya in the current political situation; however, future research might involve conducting in depth interviews with clinicians in various regions that would be accessible. The study provides some information regarding what could be considered as standard care or usual care. This could be used to assist with the design of a UK based randomised controlled trial of a multimodal intervention for fibromyalgia and investigating such aspects as dose and duration of exercise interventions. The few RCTs that have been undertaken have shown equivocal results and have lacked standardisation.

6.2 Recommendations for Policy and Practice

From both the survey and the interviews, it is clear that there is a variability of services in the UK available to people with fibromyalgia and it is difficult to ascertain what standard care or usual care entails. At present, there are EULAR recommendations for fibromyalgia (Macfarlane et al., 2017, Carville et al., 2008a) however; there are few specific guidelines particularly regarding dose and duration of available interventions. There is also varying availability of services and patients have often experienced symptoms for some time before they have been diagnosed and are thus more difficult to treat. It is recommended that patients are referred at an early stage to a specialist clinician and receive information, advice and support perhaps from a multidisciplinary team. There was general agreement amongst both patients and the health professionals that maintenance of physical and daily functioning is essential otherwise getting tired will keep them in bed for up to three days' after and be detrimental to physical and psychosocial functioning.

Service users need to have reliable and informed knowledge and education about chronic widespread pain /fibromyalgia and providers need to also understand the variable presentation and effects upon different patients, who may have multiple co-morbidities and varying clinical presentations and response to interventions. It is also suggested that there is a need for education and awareness particularly in the primary care setting, and also a more standardised approach to management and onward referral if appropriate.

Ideally, face-to-face interviews with HCPs in Libya may be preferable to operationalize the in-depth interviews in the future, although this is likely to be resource intensive and to produce a better understanding of the condition occurrence and health care professionals' attitudes regarding recognition of widespread chronic pain (CWP) in Libya. Only by conducting more epidemiological studies in the developing world will we be able to understand the determinants and distribution of CWP worldwide fully.

6.3 Limitations

A limitation of the study is its small sample size and, for the qualitative study, its geographical restriction to one site , albeit a large region that was covered by the local fibromyalgia group and which fell under various NHS Trusts with differing practices and services for fibromyalgia.

There was a disappointing response to the postal survey from the British Pain Society. In addition, there was a very considerable delay in response from the BPS regarding the agreement which was made between BPS and Northumbria University and BPS to purchase a list of email members (address labels) in order to distribute the questionnaires. Originally, it was intended to start with the survey and use the findings to inform the development of the interview schedule for patients, however, due to this delay of almost one year, it was necessary to commence with the interviewing patients as the first phase of the study. The design of the survey was adapted to allow for more open questions and exploration of responses to questions. Perhaps a link to an online survey may have produced a better response rate.

The limitations of section B (Libyan sample) included using a convenience sampling method as there is no infrastructure or comparable organisation to the BPS in Libya.

A further methodological limitation is the number of participants in the study, concerning the restriction of gathering Libyan participants, causing a lack of theoretical saturation. The limitations of section B (Libyan sample), after contacting the participants by email and handing the questionnaire to the HCPs in Libya by the principal researcher and due to the politic situation in Libya there were limitations of collecting the sample and the responder rate was restricted. Clearly, there is a need for epidemiological studies that estimate the prevalence of chronic widespread pain in Libya to determine the scale of the problem. It was valuable to conduct the parallel survey on chronic widespread pain in Libya in order to compare results from different healthcare professionals practice, gain a broad view of the differences in approaches to the management of chronic widespread pain.

6.9 Reflections of Undertaking the Study.

My experience was based on managingof chronic pain conditions, where I provided physical and psycho-social support for people who have experienced difficulties associated with chronic illness . Individuals that I have worked with have been diagnosed with a variation of chronic pain, for instance, chronic neck and back pain, stroke, multiple sclerosis and joint pain.Referrals to the specialist could come from GP surgeries and other Health social services. My reflection demonstrate that the purposeful design of this mixed methods study captured service users and service providers views and experiences in UK and Libya.

Undertaking this qualitative and quantitative research study has been a valuable learning experience of exploring the phenomena of both experience of living with chronic pain and the interventions approaches currently used for such chronic pain. I have expanded understanding of the nature of research process and using the multiple phase study to gain deep consideration of what is been going in the domain for the topic undertake and understand the sometimes messy nature of the research process. Although involved in The research development sessions I have attended provided me with more learning skills, as well as adopting the skills provided. Learning new skills in the journey of the research study is a rational approach and helped to open a new way of understanding, not just the new skills, but also familiarisation with the data collected and the relationship between knowledge, learning and approaches efficiency.

This research study has also provided some key concepts which have helped me examine my own academic and professional values, and strategies for possible fluctuations to my own future practice.

My reflections over the design and process of waof conducting research and the utility of the research projectunderpins both philosophy and practice and synthesised the perspectives in both lived with chronic widespread experience and practice explored in this research.

The purpose of using semi--structured interviews is that to enhance the understanding the individuals features of experience of living with chronic pain. I was able to develop my skill and confidence in designing and developing the research instruments to address the research topic and develop my confidence and reflect upon the process of gathering the data. . I found that participants did not struggle with my English language understanding, their responses and positive feelings that made me confident to complete the twelve interviews, also encouragement, and support from my supervisors had a huge impact upon my experience and confidence of conducting qualitative interviews.

From the beginning of the interview, welcoming the participants, I was very active in conducting the interview with a smiley face and eye contact. I also watched every step of their response, understanding the questions and keep maintained the schedule flow so that the interview could be completed with comfort and satisfaction of theme. In addition, I tried to follow the interview strategy with them. People with chronic pain can tell what they feel is going in their body, living with pain all over the body that majorly affects their life and I found the description of their pain to be horrendous. For example, from the first interview, the participant described her pain annoyed more than anything else describe and acutely had a significant impact on her life. It just everything in the whole body because of not a hundred percent well and having consent pain, struggling to do any stuff and get depression because of that and more generally tiredness. The work issue was her first concern to face with her manager because of long term sick in winter, and she had been advised to apply for retirement on health ground. However, people with long-term condition they do not expect early retirement because of their pain, as the participant thought she, not that ill bout a long time realised she was that ill. Because of the severity and verities of

symptoms of such illness and the influence of pain levels upon daily living activities. If I would not listen to patients' stories, I could not presume how much they were suffering. It is very challenging to deliberate patients understanding, as they could not express themselves, patients were frustrated because of the lack of support, I would offer some help to them to improve physical functions if it is possible. Form patients' perspectives I would be convinced that this is a real condition as a result of interviewing these patients and gathering depth views of experiences. I think either patients or healthcare professions poorly understand the condition, despite the unknown causes of this illness people involved in the long journey of diagnosis, varieties of testing and non-standardised intervention approaches, because of these, patients developed psychological issues such as anxiety and depression. Thus the journey of understanding the condition started with immersing myself in their stories and their narrative and helped my familiarisation with the data.

Individuals whom I interviewed currently had a multitude of presenting chronic widespread pain, fibromyalgia and physical and psychological concerns, including involvement or lack of availability of specific interventions. I was conscious from the literature that unclear aetiology of the condition with unstandardized interventions. Individuals portrayed different expression of living with pain, and found the support group to be very helpful.

The compounding of the illness background and patients' experience of the condition requires medical and other health care professional s to be cognisant of the range of emotional, psychological and physical factors associated with fibromyalgia in order to be able to apply effective interventions and support to patients with a diverse range of symptoms and co-morbid factors. This may involve appropriate assessment on a number of domains and a more targeted and individualised approach to interventions. The use of a specialised programme may also be recommended.

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Appendices

APPENDIX 1

Research outputs

Poster

Title: Patients' And Practitioners' Views And Experiences Of Chronic Widespread Pain (Fibromyalgia) And Its Management In The UK And Libya

Mr Sedik Abokdeer, Professor Nicola Adams.

Faculty of health and life Sciences, City campus. Northumbria University, Newcastle upon Tyne. (Poster), 23th May 2015.

Abstract

Chronic widespread pain conditions such as fibromyalgia (FM) are prevalent and costly to the economy. Diagnosis is based upon symptoms and although its existence as a distinct clinical entity is debated, it causes great suffering and distress for those affected.

Due to the unclear pathophysiology, controversy regarding its existence as a clinical entity and variability in diagnosis, clinical management if often difficult, and frequently employs heterogeneous interventions The purpose of this research study is to describe current practice for fibromyalgia in the UK. It also aims to capture service users' and service providers' views and experiences of fibromyalgia and its management.

A mixed methods approach will be used. In Phase 1 an online, specifically designed survey will be distributed to rheumatologists, pain management and physiotherapy clinics in all regions of UK using extant databases. In the second phase semi-structured interviews will involve a sample of people suffering from FM recruited from the fibromyalgia self-help group in the North East.

From this study, current practice for fibromyalgia in the UK will be elucidated. Implications in terms of current practice, and participants' experiences will be explored including their emotional and lived experience, information seeking and experiences of seeking and receiving health care.

Presentation

Title: Service Users and Service Providers Views and Experiences of Chronic Widespread Pain Conditions Practice and Participation.

Mr Sedik Abokdeer, Professor Nicola Adams, Dr, Jenni Monghan

Faculty of health and life Sciences, City campus. Northumbria University, Newcastle upon Tyne. (Presentation), 26th June 2017.

Abstract

Background: Chronic widespread pain and fatigue conditions such as fibromyalgia (FM) are prevalent and costly to the economy. Due to the unclear pathophysiology, controversy regarding its existence as a clinical entity and variability in diagnosis, clinical management if often difficult, and frequently employs heterogeneous interventions. People with fibromyalgia face challenges regarding obtaining a diagnosis and subsequent treatment.

Aim: The aim of this study (Phase 1). Was to explore the experiences of people with fibromyalgia.

Method: The study was carried out in two phases. Phase 1 consisted of twelve semi-structured interviews conducted with people diagnosed with FM. Participants also completed the Fibromyalgia Impact Questionnaire (FIQ) and Toronto Alexithymia Scale (TAS) Phase 2 consisted of a national survey of health and medical professionals from the British Pain Society regarding their views and management practices of fibromyalgia. This study focuses on the findings of the qualitative interviews in Phase 1. The sample for Phase 1 were recruited from the fibromyalgia self-help group in the North East. Framework analysis was used for the analysis.

Findings: The analysis focus on participants experience of living with fibromyalgia and their experiences of obtaining a diagnosis, pain management by health professionals, ways of coping with the condition and its impact on their daily lives. . The main themes identified were: The following themes were identified: Implications in terms of participants' experiences were explored including their views of journey of diagnosis, current practice availability, emotional and lived experience, information seeking and experiences of seeking and receiving health care in the UK. The primary qualitative study highlighted some difficulties participants faced regarding a perceived lack of understanding by health and medical professionals and also the general public regarding management of the condition and the emotional and physical impact of FM. This lack of understanding often led participants to avoid going back for further health and medical intervention. These findings suggested people were not managing the daily living activates regarding to symptoms such as disabling fatigue and worsening pain. This part of the study has illustrated a variety of intervention approaches are used with varying and often limited success. The participants' perspectives have illuminated the need for support required for people living with FM and need for education and standardisation of approaches in clinical practice.

APPENDIX 2

Department of Sport, Exercise and Rehabilitation ethics proses – conformation letter of ethical approval

Appendix

A project Approval letter

12/05/15

HLSSA300415

Patients' And Practitioners' Views And Experiences Of Chronic Widespread Pain (Fibromyalgia) And Its Management In The UK And Libya

Dear Sedik,

I can confirm that the above-named project has received ethical approval through the Department of Sport, Exercise and Rehabilitation ethics process.

Please retain this letter for your records.

Yours Faithfully,

Dr Mick Wilkinson (Ethics Chair)

Mick Wilkinson, PhD, MSc, BA (Hons), FRSS

Senior Lecturer,

Department of Sport, Exercise and Rehabilitation

T: +44 (0)191 243 7097

E: mic.wilkinson@northumbria.ac.uk

NB225, Northumberland Building, Northumbria University, Newcastle upon Tyne, NE1 8ST, United Kingdom

Appendix

Project Amendment Form

Project Title: Patients' And Practitioners' Views And Experiences Of Chronic Widespread Pain (Fibromyalgia) And Its Management In The UK And Libya	**Date original ethical approval received**: 12/05/15
Principal Investigator: Sedik Abokdeer	Project ref: HLSSA300415
Date: 22/02/2016	
Description of Amendment/Change: The administration of the Fibromyalgia Impact Questionnaire in addition to the interview. FIQ were derived from information gathered from patient reports, functional status instruments and clinical observations. Impact Measurement Scale (AIMS) was used to assess the content validity of 10 items which consisted of work difficulty, feeling good, pain fatigue, rest and stiffness. Burckhardt, C.S., et al. (1991). Bennett, R M et al (2009). The degree of correlation between change in FIQ scores and change in patients will be compared. <u>Reference</u> Burckhardt, C.S., Clark, S.R, & Bennett, RM. (1991). The Fibromyalgia Impact Questionnaire: Development and validation. Journal of Rheumatology, 18, 728-734. Bennett, R M, Friend R, Jones D K, Ward R, Han K B & Ross L R (2009) the Revised Fibromyalgia Impact Questionnaire (FIQR): validation and psychometric properties Arthritis Research & Therapy 2009, 11: 4 , R120	
Reasons for Amendment/Change: To assess their function and impact of fibromyalgia to augment the qualitative data. The validity of Fibromyalgia Impact Questionnaire measuring patient's' subjective responses will continue to be important and anticipate to use the FIQ in a large clinical trial. This phase wasn't included before is because is still under discussion.	
Anticipated Implications: The anticipated implications are that it will extend the timescale of the interview by another 5 minutes; an overall time of the data collection of interview and Fibromyalgia Impact Questionnaire will be 45 minutes to 50 minutes roughly.	
Acceptance	Signature: M. Uil~.
Date: 22/02/16	

Appendix

Follow-up action passed to:
Reason for Rejection:

APPENDIX 3

Fibromyalgia Support Group agreement letter

Agreement Letter

NEWCASTLE-UPON-TYNE
FIBROMYALGIA
SUPPORT GROUP

12 Wheatfield Grove
Benton
NEWCASTLE-UPON-TYNE
NE12 8DN
Email: newcastlefibro@gmail.com
Website: www.fibromyalgia-newcastle.co.uk
Tel: 0844 887 2433

29th January 2015

Dear Sir or Madam

TO WHOM IT MAY CONCERN

Re: Research Study: Service Users and Providers Views and Experiences of Chronic Widespread Pain Conditions (Fibromyalgia): Practice and Participation

Principal Investigator: Professor Nicola Adams

PhD Student: Sedik Abokdeer

I am writing to confirm that our support group has been consulted regarding the above study by the principal investigator and we have agreed to be involved with the study. We understand what is involved and also that we are in no way obliged to participate and that we may withdraw at any time.

Yours faithfully

Fiona Gaskin-Colligan
Treasurer & Secretary

APPENDIX 4

Invitation Latter for Interview Phase 1 of the Study

Invitation Letter

Faculty of Health and Life Sciences

PGR Room 431

Northumberland building

City campus

Northumbria University

Date March 2015
Newcastle upon Tyne

NE1 8ST, UK

Dear <<TTILE>> <<SUNAME>>

My name is Sedik Abokdeer I am qualified BSc physiotherapy Worked with a background in Low back pain management, and MSc in health and social care (physical therapy specialist). At present, I am a full-time doctoral student in affiliation with Northumbria University. For my doctorate, I am undertaking research that looks at issues of 'fibromyalgia' interventions to people exhibiting interventions performances that have historical and/or present involvement with Local Authority health Services.

On the basis of your present position I have identified you as being involved in the provision of collaborative health services to this intervention and/or as a helper of investigation that inform and/or impact upon the life course of these fibromyalgia syndrome patients.

I am writing to ask you take part in a semi-structured INTERVIEW conducted by me. The purpose of this interview is to better understand your present experience or organisational involvement with these interventions, as well as your perceptions of how your involvement(s) impact of interventions upon the life course of this population with fibromyalgia syndrome.

I have attached an information sheet and informed consent to this email. **If you are interested in participating I would ask that you take the time to review the accompanying Information Sheet and return the attached INFORMED CONSENT care of my attention as confirmation of your willingness to participate.** In-kind I will be in contact so as to agree a date, time, and location that suits you for purposes of facilitating this interview. If you have any questions please do not hesitate to contact me directly.

This study has received ethical approval from the Faculty of Health and Life Sciences Ethics Committee at Northumbria University.

Sincerely,

Sedik Abokdeer

PhD student Researcher

M: 07448378709

sedik.abokdeer@northumbria.ac.uk

APPENDIX 5

Patients consent form to participate in the phase 1 study

Consent form

Project Title: - Service Users and Service Providers Views and Experiences of Chronic Widespread Pain Conditions (Fitzcharles et al.): Practice and Participation.

Named Researcher: MR: Sedik Abokdeer

PhD Researcher

M: 07448378709

Sedik.abokdder@northumbria.ac.uk

This form is designed to confirm that you have been fully informed about the research being undertaken, that you understand what you are being asked to do and that you consent to participate in the research.

Please INITIAL the boxes that correspond to your choices	YES	NO
1. I wish to participate in the INTERVIEW associated with this research.		
2. I have read & understood the attached information sheet giving details of the project.		
3. I have had the opportunity to ask any questions about the research, my involvement in it, and am satisfied with the answers I have been given.		
4. I am aware decision to consent is entirely voluntary and I understand that I am free to withdraw at any time without giving a reason.		
5. I understand that if I elect to withdraw from participating in this research my decision will not impact upon my standing with the organisation for which you work		
6. I understand the data gathered in this project will form the basis of a doctoral thesis and may inform reports and/or publications and/or presentations.		
7. I understand that my name will not be used in the named researcher's thesis and in any other report, publication, and/or presentation resulting from the data collected, and that every effort will be made to protect my confidentiality.		
8. I consent to being audio recorded for purposes of data collection.		
9. I know that if I am in any way unhappy with the conduct of the research, I may approach **Professor Jennifer Watling**; Associate Dean for Research and Innovation; Northumbria University; Coach Lane Campus, Benton; Newcastle upon Tyne; NE7 7XA; Tel:- 0191 215 7771 email : - Janice.armstrong@northumbria.ac.uk		

Please SIGN the following, PRINT your name, and DATE

Participant's Signature: ----------Date: -----/------/-------

Participants Name (in CAPITALS): ----------

The named researcher signs/dates in the space provided to confirm that the participant understands the purpose of the research, their role, and that they have the right to withdraw at any time.

Researcher's Signature: ---------- Date: -------/----------/----------

CONTACT DETAILS FOR SUMMARY OF RESULTS

I would prefer to receive the results by (please tick one):

Post ☐

Email ☐

Postal address:

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……

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Email:

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APPENDIX 6

Interview Schedule for fibromyalgia patients interviews, phase 1

Northumbria University NEWCASTLE

Semi-Structured Interview Schedule

Semi-Structured to be undertaken with

Fibromyalgia Self-help Group.

Title of the Project: **Service Users' and Service Providers' Views and Experiences of Chronic Widespread Pain Conditions (Fitzcharles et al.): Practice and Participation**

Named Researcher: MR: Sedik Abokdeer

The interviews aim to derive the following information, thought a sim-structured interviews is used to capture the subjects' views and experiences and discussed freely from the schedule in order to further understanding the condition.

Time Available: 50 Minutes

This study is NOT part of any treatment programme and that they will NOT be offered any treatment as a result of issues that arise in the study.

INTERVIEW GUIDE

In this phase I will begin with asking you

What do you feel is going on in your body? Could you tell me the process of going of pain of FM (you can use images or drawings or whatever helps you to describe it to me) body map is provided.

Prompts

- Describe the feelings that you experience.
- How does this make you feel?
- How does these feeling and symptoms affect you/your life?

History/ Background /symptoms

What does the Fibromyalgia mean to them? Tell me about the History symptoms that you feel?

Prompts

- How long do you remember having symptoms?
- What made you seek medical help?

- What was the response of your doctor?

Diagnosis

What does the diagnosis mean to them, tell me how you feel when you were diagnosed with fibromyalgia?

Prompts

- How long before you were diagnosed
- When were you diagnosed?
- What information did you get on your condition and from whom?

Current state

What impact has fibromyalgia had on their quality of life? “How has fibromyalgia?

affected your life"

Prompts

- What are your worst symptoms?
- If you had to choose a symptom to treat, what would be your priority?
- Can you tell me what treatment/interventions you have had for your condition?
- When do you get support and help with your condition?

Treatment

What treatments do patients with fibromyalgia use to manage their condition?

Prompts

- How helpful do you find your interventions?
- What do you think works best for you? Is it referring to medication, treatment, and exercise or pain management?
- Why do you think of interventions works best for you?

NHS experienced

How they feeling about services been received from NHS? What they expect to receive?

Prompts

- Can you tell me about your experience of treatment within the NHS?
- Is there anything you would like to have included in your treatment that you did not have?
- Are you still receiving treatment from the NHS?

Gaps in treatment

How they think about other service can be more help from those organization who involving in manage their condition.

Prompt

- Is there anything else that could be done e.g. in the community/leisure/Governmental level that you feel would help you?

Private /alternative treatment

Who they seen in privet sector?

Prompt

- Do you see anyone privately (e.g. a CAM therapist)

Deal /future treatment / management

What kind of interventions they may chose for manage their condition?

Prompt

- If you could choose your own package of care, what aspects would you choose?

Anything else

What is more information they are think is important to be mentioned about their experience of living with fibromyalgia?

Prompt

- Is there anything else you would like to tell me about your experience of fibromyalgia?
- Is there anything else you would like to add that has not been discussed?

Closure of interview

Thankfulness

Thank you very much for your participation

APPENDIX 7

Participations information sheet interviews, phase 1

Northumbria University NEWCASTLE

INTERVIEW INFORMATION SHEET

Project Title:

Service Users and Service Providers Views and Experiences of Chronic Widespread Pain Conditions (Fitzcharles et al.): Practice and Participation.

INTERVIEW INFORMATION SHEET

We would like to invite you to take part in our research study which involves taking part in an interview about your experience of interventions for fibromyalgia. We have provided this information sheet to help you understand why the research is being done and what it will involve for you before you decide whether to take part or not. This would take about 10 minutes to read. We would like you to read the information carefully and discuss it with other people if you wish. You are very welcome to speak to Sedik Abokdeer, the researcher if you need more explanation or more information

What is the research about?

The purpose of this research is to help us explore the influences that make some people take part in interventions for fibromyalgia and the factors that make others not to take part. The research also aims to explore the types of interventions that you have found to be useful and why and the types of interventions and services you would like to receive. So, we are interested in your views and experiences your 'voice' on this matter.

Why have I been asked?

You have been asked because you have been diagnosed as suffering from fibromyalgia and are attending a self-help group in the region.

What am I being asked to do?

You are being invited to participate in a semi-structured INTERVIEW facilitated by the named researcher. This interview is estimated to be 45-60 minutes in duration. You will be asked to share from the perspective of your experiences in been live with condition and working with fibromyalgia self-help group exhibiting interventions conducts who have a history of and/or current involvement with local authority health services. The interview will take place at a location of your choice. It could be in a local private meeting room arranged with the researcher or at your home. If the interview is not held at home, any travelling expense incurred to get to the interview venue will be fully reimbursed.

At the interview, the researcher will first review this information sheet with you and answer any questions you may have. The researcher will then ask you to sign the consent form if you are happy to continue to take part in the research. The researcher will then ask you some questions regarding your thoughts and views about the fibromyalgia interventions programme (the physical activates) and your participation in the research.

The interview will be audio recorded with your permission, and the researcher and interviewee will be present in the interview room.

What happens if I do not want to participate?

Participation is completely voluntary. It is entirely up to you to decide if you would like to take part.

What would happen if I agree to participate and then change my mind?

You are under no obligation to take part and if you do decide to take part, you are free to withdraw at any time if you change your mind without giving a reason. However, the data collected from the interview will still be used in the research with all personally identifiable information removed. It will not be possible to withdraw the data at this stage. If you have already communicated interest and agreed to participate, kindly contact the named researcher to decline your interest.

Will my participation in the research be kept confidential?

Yes, you taking a part in the research will be kept confidential, only the research team will know about your participation in the research; all personal data will be kept confidential and will not appear in any printed documents associated with this research.

What will happen to the information that is gathered from the interviews?

All the information collected will be kept confidential. After the interview, the researcher will keep up the information with your code and any other identifiable information secured behind lock and key at Northumbria University accessible to only the named researcher and/or encrypted electronically. Only the research team will have access to this information. Any quotes that are used in the final report will be anonymised. Names and details of participants will not appear in any printed document. Case report forms (CRFs) - i.e completed interview data will be stored securely in a locked cabinet at the Northumbria University and destroyed a year after the end of the research, data can be withdrawn of the request is made before a specified deadline.

What will happen to all the information collected for the research and how will the research report be disseminated?

All the information collected will be looked at to identify participants common thoughts and views and about the interview transcription sheet. These will then be used to produce a final report. The final report will be presented to the Northumbria University. This final report will form part of the researchers Ph.D. degree. A summary of the research finding will be sent to all the participants and the full report can be requested by the participants after the final report has been produced. The research findings will also be disseminated to the UK Strategic Health Authority, who may wish to publish the results on their website and newsletter.

It is anticipated that peer-reviewed publication and national/international conference presentation may also arise from this study.

Who will read and/or have access to the published results?

This research will be used in the named researcher's doctoral thesis. Following the completion of this thesis faculty, staff, and students affiliated with Northumbria University will have access to the thesis and its contents. Additionally it is the named researcher's intention to make the conclusions of this research available to the local authorities and other organisations participating in an effort to both inform health work practice, as well as to improve the services currently afforded the fibromyalgia patients of concern.

Who can I contact if I want to know anything else about this study?

You are most welcome to contact the named researcher and/or the named researcher's project supervisor if you require further information relative to this study. Contact information for both parties is as follows:

PROJECT SUPERVISOR	NAMED RESEARCHER
Prof Nicola Adams	**MR Sedik Abokdeer**
Faculty of Health and Life Sciences	Faculty of Health and Life Sciences
B131	PGR Room 431
Coach Lane Campus West	Northumberland building

Appendix

Northumbria University
Coach Lane
Benton
Newcastle upon Tyne
NE7 7XA
0191 215 6620
nicola.adams@northumbria.ac.uk

Northumbria University
City campus
Newcastle upon Tyne
NE1 8ST, UK
07448378709
sedik.abokdeer@northumbria.ac.uk

1. **Who can I contact if I am unhappy with the conduct of the research?**

If you are in any way unhappy with the conduct of the research, you may approach:

ASSOCIATE DEAN OF FACULTY

Professor Jennifer Watling
Northumbria University
Coach Lane Campus, Benton
Newcastle upon Tyne
NE7 7XA

Tel. 0191 215 7771
Janice.armstrong@northumbria.ac.uk

APPENDIX 8

Fibromyalgie Impact Questionnaire (FIQ)

Appendix

FIBROMYALGIA IMPACT QUESTIONNAIRE (FIQ)

Dear <<TTILE>> <<SUNAME>> Date: March 2015

Instructions: For questions 1 through 11, please circle the number that best describes how you did overall for the past week if you do not normally do something that is asked, cross the question out.

	Always	Most	Occasionally	Never
Do shopping?	0	1	2	3
Do laundry with a washer and dryer?	0	1	2	3
Prepare meals?	0	1	2	3
Wash dishes/cooking utensils by hands?	0	1	2	3
Vacuum a rug?	0	1	2	3
Make beds	0	1	2	3
Walk several streets?	0	1	2	3
Visit friends or relatives?	0	1	2	3
Do garden work?	0	1	2	3
Drive a car?	0	1	2	3
Climb stairs?	0	1	2	3

12. Of the 7 days in the past week, how many days did you feel good?

0 1 2 3 4 5 6 7

13. How many days last week did you miss work. Including housework, because of fibromyalgia?

0 1 2 3 4 5 6 7

Continued……..

FIBROMYALGIA IMPACT QUESTIONNAIRE (FIB)- page 2

Directions: For the remaining items, mark the point on the line best indicates how you felt overall for the past week.

14. When you worked, how much did pain or other symptoms of your fibromyalgia interfere with your ability to do your work, including housework?

__I__I__I__I__I__I__I__I__I__

No problem with work Great difficult with work

15. How bad has your pain been?

__I__I__I__I__I__I__I__I__I__

No pain Very severe pain

16. How tired have you been?

__I__I__I__I__I__I__I__I__I__

No tiredness Very tired

17. How have do you felt when you get up in the morning?

__I__I__I__I__I__I__I__I__I__

A work well rested A work very tired

18. How bad has your stiffness been?

__I__I__I__I__I__I__I__I__I__

No stiff Very stiff

19. How nervous or anxious have you felt?

__I__I__I__I__I__I__I__I__I__

Not anxious Very anxious

20. How depressed or blue have you felt?

__I__I__I__I__I__I__I__I__I__

Not depressed Very depressed

Thank you very much for your participation

APPENDIX 9

Self-report measurements Sheet Toronto Alexithymia Scale (TAS)

Appendix

Self-report measurements Sheet. Toronto Alexithymia Scale ((TAS)

		F1	F2	F3	F4	F5
Difficulty Identifying Feelings		***Very slightly or not at all***	***A little***	***moderately***	**Quite a bit**	***extremely***
1	I am often confused about what emotion I am feeling.	☐	☐	☐	☐	☐
3	I have physical sensations that even doctors don't understand.	☐	☐	☐	☐	☐
6	When I am upset. I don't know if I am sad, frightened, or angry.	☐	☐	☐	☐	☐
7	I am often puzzled by sensations in my body.	☐	☐	☐	☐	☐
9	I have feelings that I can't quite identify.	☐	☐	☐	☐	☐
13	I don't know what's going on inside me.	☐	☐	☐	☐	☐
14	I often don't know why I am angry	☐	☐	☐	☐	☐
Difficulty Describing Feelings						
2	It is difficult for me to find the right words for my feelings.	☐	☐	☐	☐	☐
4	I am able to describe my feelings easily.	☐	☐	☐	☐	☐
11	I find it hard to describe how I feel about people.	☐	☐	☐	☐	☐
12	People tell me to describe my feelings more.	☐	☐	☐	☐	☐
17	It is difficult for me to reveal my innermost feelings even to close friends.	☐	☐	☐	☐	☐
Externally-Oriented Thinking						

5	I prefer to analyse problems rather than just describe them.	☐	☐	☐	☐	☐
8	I prefer to just let things happen rather than to understand why they turned out that way.	☐	☐	☐	☐	☐
10	Being in touch with emotions is essential.	☐	☐	☐	☐	☐
15	I prefer talking to people about their daily activities rather than their feelings.	☐	☐	☐	☐	☐
16	I prefer to watch“light“entertainment shows rather than psychological dramas	☐	☐	☐	☐	☐
18	I can feel close to someone, even in moments of silence.	☐	☐	☐	☐	☐
19	I find examination of my feelings useful in solving personal problems	☐	☐	☐	☐	☐
20	Looking for hidden meanings in movies or plays distracts from their enjoyment.	☐	☐	☐	☐	☐

Thanks for your participation

APPENDIX 10

Sample of transcript Fibromyalgia patient's transcript from study 1

Sample interview 9/3/2016

To start the interview with,

Q Can you to describe your feeling, how you feel with pain. If you could draw your feeling though this map...If you could just shadow the place that you have pain through all the body, you know? Use the Body map just to help you to describe your feeling...

A Okay, yes. I mean, it can be anywhere. And so...It's a lot round the neck and shoulders, but it also goes across the chest as well, sort of like that. And then back. It could be anyway in the back. And hips and legs. That was where it started with me, was the legs here. And then it just... It can move anywhere. My hands are bad, can be bad. I don't know if... That's about it. It can be anywhere. Yup, anywhere. Yeah. It can be feet. Yes, it can be anywhere.

It moves, yeah. And it also depends what I've been doing. So if I've been walking a lot, it tends to be hips and legs. If I've been cooking or baking – hands and arms. So, yes, it just depends what I've been doing. I'll put arms in as well.it can be a little bit or it can be a lot where I can't move and I have to just stop and wait until it eases. If my hands are bad, they don't work, they lock. So I have to wait until they just loosen a bit and ease up. It could take about 20 minutes or so just waiting until they're loose and I can move them again.

Q So with these symptoms and the pain that you have had, how does this make you feel when you get that pain?

A Depressed, frustrated. Because I can't finish what I'm doing or if I'm out somewhere and it's my legs that hurt, it takes me a longer time to get where I'm going. It's frustrating mostly.

Q So with this pain and you get frustrated and a lot of struggling with the pain, so how does this affect your life?

A It slows it down. I can't do anything quickly, I can't do anything on the spur of the moment. I have to plan things more, plan leading up to what I want to do, say, go somewhere perhaps and then plan after it to recover to give myself a recovery period – a day or two days if it's something quite major. So there's a lot more planning. It takes me a long time to get ready in the morning to come out.So I get up very early, take pain tablets, soak my hands in hot water which helps them loosen up and move. Things like that. It all takes time, yeah. It takes more time.to warm them up, yeah

Q So with all of these symptoms and pain, I would like to ask you about the history and symptoms that you have. How long do you remember you have these symptoms?

A I went to the doctor about them in 2000 and... I think it was the end of 2009 and I got an appointment with the doctor at the hospital in 2010. It started with my legs. I thought it was something like... Because we'd had a very bad winter with lots of ice and walking on ice you tense up your muscles so that you don't fall, but my legs relaxed again. They never were without pain after that and I thought it was something to do with that, but the doctor asked me about pain elsewhere, which I did have, I just didn't connect it and he said it sounds like fibromyalgia because those are all the places that people get pain when they have fibromyalgia. I hadn't heard of it before so when he said that, and I paid attention to my pain, it was right. The GP referred me to the hospital and I got the appointment in 2010, so that was the doctor at the hospital. The GP didn't have any idea. He just didn't know. The GP just didn't know. He said, "I've got no idea so I'll refer you on." But the doctor at the hospital knew all about it so he had a lot of patients with it and he said, "There isn't a test for fibromyalgia." But he said, "Well, I'll X-ray you," which he did, X-rayed. And he said, "We have to rule out things, look for other things like arthritis or..." And he said, "It's not that so it's..." He says, "I think it's fibromyalgia."

Q what made you seek medical help?

A Because the pain was quite bad still and it never eased off. It was just always there and just taking something like Paracetamol didn't help, so I had to learn to... I got other painkillers, but I just had to learn to, if the pain was very bad, it meant rest or stay still anyway for a little while and don't do too much. You have to just do a little bit at a time.

Q How long before you have been diagnosed? How long you experienced of pain? And do remember when you were diagnosed exactly?

A I would say about six months. It was summertime. It was... I think it was June or July, it was June or July. I didn't bring any of my notes with me, I should have. For dates and things. It took about six months to get the referral appointment, I think, so yeah.That's what made me think as well. When the winter was just about finished, the pain wasn't going away so I wondered what it was.

Q So when you been referred to the hospital, to see the specialist, was it a rheumatologist or other specialist?

A Yes, a rheumatologist.

Q And with the rheumatologist in the hospital. What information you get about your condition? Fibromyalgia. How did you get the information through?

A The doctor at the hospital gave me a couple of leaflets. And that explained what it was and where it was likely to occur in the body and... It didn't offer treatments, but it just explained

what it was. So that's how I learned what it was I looked... Once I got home after that, I did look it up on the computer, but I stopped doing that because everything I read about, every person that I read about, they all ended up in a wheelchair. So I stopped looking it up on the computer.

Q So what are your worst symptoms that you had?

A The worst ones ever? The worst ones, I suppose, were when... one day when I couldn't walk. I mean, I could just about get round my flat holding on to the furniture, but I couldn't go outside, I couldn't... Everything hurt, everything. One makes the other worse. If I'm depressed, I tend to be in more pain. If I have a lot of pain, then it's depressing and frustrating and... Yes, those things.Tired? Yes, yes. And people don't believe how tired you can possibly be.

Q So with all of these symptoms. Can you tell me about the treatments and interventions that you had to manage these symptoms?

A I've been through a lot of different tablets, painkillers, to find the right ones and I think now it's probably the combination that helps the most. I mean, Paracetamol I do take. Wait a minute and I'll tell you. Duloxetine. Yeah, it's a mixture. I tried Gabapentin and that didn't work so I tried Pregabalin and that doesn't work by itself, but it works with other things. Duloxetine is one.With, with... Not the Gabapentin, they stopped that one.I've got Pregabalin, Duloxetine, some Codeine. I mean, it's not just one thing that works with the fibromyalgia. It's different.

Q So do you have other morbidity conditions with fibromyalgia?

A The diabetes was diagnosed the year before in 2009, in January 2009.

Q So you have been through lots of medications. Have you been on other interventions?

A I've had psychologist interventions to try and work out non-medical ways of coping. So things like mindfulness, relaxation techniques, including just relaxing in a comfortable position with or without music or with or without trying to do a self-hypnosis thing in my head – talking myself into it.Or things like a repetitive... Like knitting. If my hands will knit, I knit sometimes because just... It distracts and sometimes it can take my mind off the pain.

Or colouring. Colouring's a big thing. So sometimes I could do those just to take my mind off it and think about something else.

Q So when you are being engaged with other works, the pain is going off a bit and you feel settled down a bit? And did you find this helpful?

A Yes, yes. If I can break it, then sometimes it stays away. It's breaking it. Yes, it was good. And the psychology also talked a lot about pacing. Just doing enough and not doing too much. And if you feel good one day, don't suddenly think, "I can do everything, go back to normal" because the next day you'll be crippled and it takes longer to recover, which... That was very useful because you do think, "Oh, I'm feeling really good today. I can do everything – go everywhere, do everything," but then the next day or two days or three days, you can't move. It takes longer. Just a little bit, just a little bit. If you feel good, do a little bit more, but not kill yourself in a day.

Q So when did you get support for your condition?

A When I went to the pain clinic. I asked to be referred to the pain clinic when we were doing different tablets, trying different tablets, and they suggested the Duloxetine as well as the psychologist. And there was a physiotherapist there as well with the psychologist and she gave me some exercises to do, which sometimes help and sometimes don't. Got information on mindfulness – what it is and how to do it. And relaxation and I got tape... not tapes, but CDs. With mindfulness, I don't know what you call it. Someone talks and you listen and it helps you get into that state. One for mindfulness and one for just general relaxation.

Q So how did you find that intervention you had?

A It was more or less the same time. I think I got the psychology... I had a few psychology appointments first and then she referred me to the physio that was in the same place. It's in the same practice. So then I had a psychologist appointment and a physio appointment sort of one after the other. I had quite a few. I think I had six or eight psychology appointments and about... over a year and about three or four physio appointments. And, always the same psychologist and always the same physio. Yeah, it was very helpful, yes.

Q So what do you think worked best for your conditions?

A Finding the right combination of tablets, but with the relaxation things I got from the psychologist and the idea about pacing my energy and not using it up in one day. I think that's the most useful. And the fact that if you have to go to sleep, you have to sleep. Don't try and not sleep because, well, you probably can't do it anyway, you probably can't stay awake if you need to sleep. In the daytime I'm talking about, as well as night. It's really letting your body tell you what it wants. You know, if I have to rest, I have to rest or sleep. Yeah, usually I do sleep. I can sleep 24 hours! Fantastic, but I make myself get up in the morning because I really don't want to. I want to stay in bed and sleep and sleep, but I don't want to do that and miss out on the world.I can fall asleep on a 15-minute bus ride from my house to my mother's house.

Q So you have been through GP, specialists, physiotherapists, psychologists – can I ask you about your experience with the NHS?

A NHS in general, it's been very good for me. Very good for me, yes. I mean, I know NHS has its problems, but... and I've had to wait for some appointments if I've been referred, but generally it's been very good, very good. The GP, you know, didn't have a clue about fibromyalgia, didn't have a clue about what my pain was. Well, alright, but he did at least say,

"I'll refer you" so... And I had to wait a few months for that but, I mean, at least I got the appointment. I did asked for referral? Well, no, I just went to see the GP if he could tell me what it was and he said he didn't know so he would refer me. I went back to the GP and asked GP, yeah. I asked for the pain management referral once I knew it was fibromyalgia and we were trying different drugs, because the rheumatologist sent him a letter advising him.

Yeah, so the rheumatologist has been advising the GPs to send you to the pain management.

That's what I need to get, yeah. So that's it, that's it, yeah. So between all of these clinics that you have been visiting before, what's the variety from this to this? So is there any differences between them or...? You have... You mentioned the GP doesn't know about the fibromyalgia. Oh, yeah. The GP doesn't have any idea.Yes, the GPs don't know about everything. I mean, I've had other medical conditions in the past. The GP didn't know about anything about gynaecology either when I had problems with that. Nothing to do with fibromyalgia but, fortunately, he referred me for that as well because that required surgery.

So I guess the GPs don't have an idea about every single thing, that's all I can think of. I mean, maybe they... I don't know if it's reasonable to think that they should have an idea about everything.

Q So you tell me about this experience of visiting clinics so... and going for the treatment. Is there anything you would like to include?

R I don't think so. The pain-management people, all of those people were very good. I mean, the consultant that I saw first and then the psychologist was really good and physio. They were very helpful, very good .And when I asked to be referred, I mean, the GP said that was fine so there was no argument, so that was good. Make sure that GPs have more information because... I mean, I was lucky and, you know, he referred me more or less straightaway, but I know people don't get that support and help, so I think more information would be good. Some GPs I know don't believe it, believe in it. Yeah, so I've got a different GP because that one retired and this other one, she's okay as well. So...This new one's a bit better. The old one was older. No, she's good about it. I mean, she recommended that I be put on sick pay because I was... I couldn't manage work, I just couldn't manage it. If my hands are no good, I can't look after somebody else because I'm not safe, especially if it's vulnerable people. And it... You know, I can't... Part of it is helping somebody clean their house, well, I couldn't do that either. I can't sometimes do that because I'm too tired or I can't, you know, get down on my hands and knees and clean a floor or... So she's put me on sick pay so that... so I'm getting sick pay at the minute. And unemployed now since a second... January 2014,I was unemployed for a year, like, on sick pay for a year and then the Atos

thing, you know, with going on long-term sick pay. I had to have interviews with those people and they put me on sick pay for another two years, which is up next March. I've got another year left of sick pay.

Q So When you've been working and do you feel pain all the time or just from time to time?

A The more I worked, the more I, you know, the worse I felt and I was just too scared to look after somebody because, you know, sometimes you have to hold on to them or even if it's a child, if I babysit for somebody, I would never... I would never, ever hold a baby now. I just wouldn't do it because I'm too frightened. Yes. It makes me feel as if I've got no, like... no purpose, I suppose. I couldn't go back to caring at the minute. I couldn't... I can't even do a computer for very long because my eyesight blurs and after 20 minutes or half an hour I have to come off the computer, so I'm not sure what job I could do at the minute. I mean, I'm glad I'm on the sick at the minute because it means I can pace myself and go to sleep if I need to and...I wouldn't be able to do that if I had to show up for a job every day.

Q So did you have a support from family and friends?

A It was... Yes. I've only got my mother here at the minute. My father died last year. That's alright. I have two brothers who live in America and I speak to them or email them. I think I've got one friend who absolutely supports me, no question, and I've got another friend who almost does, but she doesn't quite... I think she doesn't quite believe in the severity of the pain or the severity of the tiredness. I mean, she does support me, but I think there's a

tiny bit of her that just doesn't quite believe it. Official people like Atos when they do the interviews don't believe it, don't believe it. I got refused and I had to go to a tribunal.

Q Did you get any support from others?

No. I don't think there's been any support anywhere else. No information coming through other places? No. I mean, through here, this fibromyalgia group from here, which I'm very glad to have found. Any lecturers come in as a visitor? Yes, people come and talk through this, yes. it's Very helpful. It's nice to be able to walk into a room and know that everybody's the same as you.You don't have to explain anything. Yeah, so this has been really good.

Q So you have been in NHS and have you see anybody privately?

A No. No. just NHS, not privately, yeah?

Q So for the future, if you'd like to have a package for your condition as a treatment, what would you like to choose?

A Ooh, a package... Yeah, it is. Yes, I think it should be automatic that people get the information like I got from the psychologist, as well as drugs and it needs to be that people get the right drug or the right drug mixture combination for them, that all the doctors believe them – GP. I mean it would be great if all this just came from the GP. Maybe that's not realistic, but it should... it should come without too much of a fight for people. Drugs, relaxation, the psychology advice, relaxation exercises, mindfulness. Pacing, make sure everybody knows about pacing – not to do too much. For me, that was a very important thing because it comes with accepting that maybe you've always got the pain, the pain might never go away. I'm just going to stand. Which at first, for me, was like defeat, you know? Just... I felt I should fight the pain more, but I think that takes too much energy and you can't... The pain's going to be there. It won't get rid of the pain so pacing is important.

Q Before we get to the end, I have a self-Report questionnaire . Can you fill this for me please?

A Right, yeah.

Q Is there anything else you would like to tell me or discuss that we haven't got through in the interview or any questions you would like to ask?

A No, I don't think so. Just to say it is... how important it is having groups like this, the fibromyalgia group. Yes, yes, very good.

Q Is there anything you would like to ask me before we end the interview?

A I don't think so,

Q Thanks very much, very much for coming. And it was my pleasure to meet you today.

Thanks a lot.

A It was a pleasure to meet you as well. I hope it's helpful.

A Yeah, it's very really... really very helpful that point you mentioned about your experience and how you get... manage through the specialist area, you know? Thanks for coming and

I'm really happy to listen to your experience. That's given me lots of key words and information, you know?

Thank You

APPENDIX 11

Agreement to Use Mailing Labels for Marketing Purposes

Appendix

19th April 2016

THE BRITISH PAIN SOCIETY (Ortega E1)

and

NORTHUMBRIA UNIVERSITY (2)

AGREEMENT TO USE MAILING LABELS
FOR MARKETING PURPOSES

1

THIS AGREEMENT is made on the 3rd March 2016

BETWEEN:

(Ortega E1) THE BRITISH PAIN SOCIETY a company limited by guarantee and incorporated in England (Co. No. 5021381) whose registered office is at 3rd Floor, Churchill House, 35 Red Lion Square London WC1R 4SG (BPS) and

(2) NORTHUMBRIA UNIVERISTY, Department of Sport, Exercises and Rehabilitation Faculty of Health and Life Sciences, Northumberland building Room 431, Newcastle Upon Tyne NE1 8ST

WHEREAS:

(A) BPS is a national society with a large membership, certain of which are happy to receive marketing material relating to the Purpose, names and addresses of which are contained on the Mailing Labels.

(B) The Labels Buyer wishes BPS to provide it with one set of the Mailing Labels to be used once only for the Purpose, subject to the terms of this Agreement.

(C) The Charity (BPS) has granted to the company (BPS Pain Business Ltd) the right to market the Mailing Labels for the purposes provided for in this Agreement. The company is a wholly owned subsidiary of the Charity, and has covenanted to pay a proportion/all of its profits to the Charity.

The mailing labels will be invoiced through our trading company BPS Pain Business

Ltd

NOW THE PARTIES HAVE AGREED AS FOLLOWS:

1 INTERPRETATION

1.1 In this Agreement the following words shall have the following meanings:

the Act means the Data Protection Act 1998 and any related data protection laws, statutes, regulations, directions and any non statutory guidance issued by the Information Commissioner's Office, as amended, revised, updated or replaced, from time to time;

Commencement Date means the date of this Agreement;

Intellectual Property Rights means all patents, topography rights, design rights, trademarks, copyright, rights in databases, sui generis rights, trade secrets and other confidential information, know-how and all other intellectual property rights of a similar nature in any part of the world, whether registered or unregistered, and all applications and the rights to apply for the protection of any of the foregoing;

Mailing Labels means the set of mailing labels with the names and addresses of all BPS members who have consented to receive third party marketing in connection with the Purpose, to be supplied by the BPS subject to the terms of this Agreement;

Marketing Law means all laws, statutes, regulations, directions and any non statutory guidance issued by the Information Commissioner's Office, the Office of Fair Trading or Ofcom in relation to direct marketing whether by post, fax, telephone, email, text message/sms, or any other electronic means, including the Privacy and Electronic Communications (EC Directive) Regulations 2003 as amended, revised, updated or replaced, from time to time;

Personal Data shall have the meaning given to such expression in the Act;

Purpose means for the purpose of marketing the specific goods or services approved in advance by the BPS and described in Schedule 1 which for the avoidance of doubt are courses, seminars, meetings or pain related products offered by the Labels Buyer (but for the avoidance of doubt, not on behalf of any person other than the Labels Buyer);

Term means the period that this Agreement is in force, until it is properly terminated;

1.2 In this Agreement references to any statute or statutory provision shall, unless the context otherwise requires, be construed as a reference to that statute or provision as from time to time amended, consolidated, modified, extended, re-enacted or replaced.

1.3 In this Agreement references to the masculine include the feminine and the neuter and to the singular include the plural and vice versa as the context admits or requires.

1.4 In this Agreement references to Clauses and the Schedules are references to clauses of and the schedules to this Agreement, and the Schedules shall be deemed to form part of this Agreement, and in the event of any inconsistency between this Agreement and the Schedules, the order of precedence set out Clause 4 shall be applied;

1.5 In this Agreement the headings will not affect the construction of this Agreement.

1.6 In this Agreement the expression "including" shall be non exhaustive and shall mean "including but not limited to".

2 BPS' OBLIGATIONS

2.1 Subject to receipt of the Fee, payable in advance in cleared funds, BPS agrees to supply the Mailing Labels to the Labels Buyer by the Delivery Date[s] set out in Schedule 1.

2.2 BPS agrees to promptly notify the Labels Buyer of the details of any BPS member who contacts the BPS indicating that they do not wish to receive any marketing material from the Labels Buyer, which the Labels Buyer agrees to promptly add to its direct marketing mailing suppression list and to immediately cease sending material to such notified persons.

2.3 For the avoidance of doubt, the Mailing List has not been checked against the Mail Preference Scheme by the BPS, which the Labels Buyer shall do before sending out any marketing material using the Mailing Labels.

2.4 BPS warrants that it has obtained appropriate consent under the Act from all BPS members on the Mailing Labels for the Label Buyer to use them for the Purpose.

3 LABEL BUYER'S OBLIGATIONS

3.1 The Label Buyer agrees that it shall only use the Mailing Labels for the Purpose, and on its own behalf.

3.2 The Label Buyer agrees that it shall not:

3.2.1 make copies of the Mailing Labels; or

3.2.2 extract or abstract any data contained in the Mailing Labels there from; or

3.2.3 create a database from the Mailing Labels; or

3.2.4 use the Mailing Labels or any information contained in them, or derived from them, for any reason other than the Purpose as permitted by this Agreement,

3.2.5 use the Mailing Labels on more than the number of permitted occasions specified in Schedule 1;

3.2.6 use the Mailing Labels within [3 months] pof the Delivery Dates, and if not so used, shall destroy them and provide evidence to BPS of such destruction upon request.

3.3 The Label Buyer agrees that it shall at all times:

3.3.1 look after any Personal Data in the Mailing Labels as confidential information and keep in place appropriate internal organisational measures within BPS against accidental or unlawful destruction or accidental loss, alteration, disclosure to any third party organisation, other unauthorised disclosure or access to any Personal Data contained in the Mailing Labels as well as reasonable security programmes and procedures for the purpose of ensuring that only authorised BPS employees have access to such Personal Data, and that any persons whom it authorises to have access to such Personal Data will respect and maintain such confidentiality.

3.3.2 comply with the Act; and

3.3.3 comply with all Marketing Law.

3.4 The Label Buyer shall immediately pass on to BPS any query, issue or correction from a BPS member, whether during the Term, or thereafter.

3.5 The Labels Buyer acknowledges that any breach of its obligations under Clauses 3.1, 3.2, 3.3 and 3.4 would have a very serious impact on the usefulness and marketability of the Mailing Labels, and/or on BPS's relationships with its members, and hence on BPS' business, and also that any such breach may in addition have severe regulatory consequences under the Act or Marketing Law, or other legislation for BPS for which damages are unlikely to be a sufficient remedy, and that accordingly BPS shall be entitled to immediately seek injunctive or other appropriate relief.

3.6 The Labels Buyer hereby indemnifies BPS in full and shall hold BPS indemnified in full against all actions, claims, demands, liabilities, damages, costs, losses or expenses incurred or suffered by BPS as result of any breach by the Labels Buyer of its obligations under Clauses 3.1, 3.2, 3.3 and 3.4.

4 LIMITATION OF LIABILITY

4.1 The following provisions set out BPS' entire liability (including any liability for the acts and omissions of its employees, agents or sub-contractors) to the Labels Buyer in respect of:

4.1.1 any breach of its contractual obligations arising under this Agreement in respect of the Mailing Labels; and

4.1.2 any representation, statement, or tortious act or omission including negligence, arising under or in connection with this Agreement in respect of the Mailing Labels

AND THE CUSTOMER'S ATTENTION IS IN PARTICULAR DRAWN TO THE PROVISIONS OF THIS CLAUSE 4:

4.2 Any act or omission on the part of BPS or its employees agents or sub-contractors falling within Clause 4.1 above shall for the purposes of this Clause 4 be known as an 'Event of Default'.

4.3 BPS' liability to the Labels Buyer for:

4.3.1 death or personal injury resulting from its negligence; and 4.3.2 fraud or fraudulent misrepresentation shall not be limited.

4.4 Subject to the provisions of Clause 4.3 above BPS' entire liability in respect of any Event of Default shall not exceed the greater of

4.4.1 such sum as BPS is reasonably able to recover from its insurer under the terms of any insurance policy for the time being in force specifically in respect of the specific loss or damage suffered by the Labels Buyer in respect of such Event of Default (the Labels Buyer acknowledging that several of BPS' customers are likely to be affected by any Event of Default, and for the avoidance of doubt also acknowledging that this condition shall not confer any rights on the Labels Buyer in respect of such policies or their enforcement); or

4.4.2 the total Fees paid for the Mailing Labels.

4.5 Subject to Clause 4.3, above BPS shall not be liable to the Labels Buyer in respect of any Event of Default for any:

4.5.1 loss of profits (whether direct or indirect);

4.5.2 loss of business;

4.5.3 loss of goodwill;

4.5.4 loss of anticipated savings;

4.5.5 loss or corruption of data;

4.5.6 Any type of special, indirect or consequential loss (including loss or damage suffered by the Labels Buyer as a result of an action brought by a third party)

even if such loss was reasonably foreseeable or BPS had been advised in advance of the possibility of the Labels Buyer incurring the same.

4.6 If a number of Events of Default give rise to substantially the same loss then they shall be regarded as giving rise to only one claim under this Agreement.

4.7 The Labels Buyer hereby agrees to give BPS not less than 28 days in which to remedy any Event of Default hereunder, and where remedied within such period, such event shall be deemed not to have been an Event of Default.

5 PRECEDENCE OF PROVISIONS

5.1 In the event of a conflict between the provisions of the main body of this Agreement, and the provisions of any other Schedule, the terms of the main body of this Agreement shall prevail, followed by the provisions of the other Schedules. For the avoidance of doubt, where the Schedules expand upon or supplement the provisions of the main body of this Agreement, they shall not be deemed to be in conflict.

6 PROPRIETARY RIGHTS

6.1 The Labels Buyer expressly acknowledges and agrees that BPS own all Intellectual Property Rights in or relating to or arising from the Mailing Labels and any related database of which they form a part, or which they form, and that it shall gain no rights in them, all of which shall at all times remain in the full ownership of BPS;

6.2 Except as expressly stated herein, this Agreement does not grant the Labels Buyer any other rights to, or in, patents, copyrights, database rights, trade secrets, trade names, trade marks (whether registered or unregistered), or any other rights or licences in respect of the Mailing Labels or any related documentation, including but not limited to the design, format and layout of the Mailing Labels.

6.3 Nothing in this Agreement shall prevent or restrict BPS from providing the Mailing Labels to any third party.

7 TERM AND TERMINATION

7.1 This Agreement shall commence on the Commencement Date shall continue automatically until after the last of the Mailing Labels has been used or destroyed in accordance with this Aggreement or otherwise terminated in accordance with the terms of this Agreement.

7.2 This Agreement may be terminated immediately by notice in writing:

7.2.1 by either party if the other party is in material or continuing breach of any of its obligations under this Agreement and fails to remedy the same (if capable of remedy) for a period of 30 days after written notice of the breach by the other party;

7.2.2 by either party, if any of the following events occurs in respect of the other party:

7.2.2.1 if an order is made or a resolution is passed for the winding up of the other party or circumstances arise which entitle a Court of competent jurisdiction to make a winding-up order of the other party; or an order is made for the appointment of an administrator to manage the affairs, business and property of the other party or documents are filed with a court of competent jurisdiction for the appointment of an administrator of the other party or notice of intention to appoint an administrator is given by the other party or its directors or by a qualifying floating charge holder (as defined in paragraph 14 of Schedule B1 to the Insolvency Act 1986); or

7.2.2.2 if a receiver is appointed of any of the other party's assets or undertaking or if circumstances arise which entitle a court of competent jurisdiction or a creditor to appoint a receiver or manager of the other party or if any other person takes possession of or sells the other party's assets; or

7.2.2.3 if the other party makes any arrangement or composition with

its creditors or makes an application to a court of competent jurisdiction for the protection of its creditors in any way; or

7.2.2.4 if the other party is, or is reasonably considered to be unable to pay its debts when they fall due as defined in Section 123 of the Insolvency Act 1986; or

7.2.2.5 if any distraint is levied against the other party or its property by any third party; or

7.2.2.6 if such party ceases, or threatens to cease, to carry on business; or

7.2.2.7 if such party suffers analogous action in any jurisdiction.

7.3 Termination of this Agreement howsoever caused shall be without prejudice to any obligations or rights of either of the parties hereto accrued prior to such termination and shall not

affect any provision of this Agreement which is expressly or by implication intended to come into effect on, or to continue in effect after such termination.

7.4 Upon termination for whatever reason the Labels Buyer shall not make any further use of the Mailing Labels without the prior written consent of BPS and shall upon request from BPS promptly return to BPS all unused Mailing Labels.

7.5 Clauses 3.3, 3.5, 3.6 and 4 shall survive termination of this Agreement.

8 COUNTERPARTS

8.1 This Agreement may be entered into any number of counterparts and by the parties to it on separate counterparts, each of which when so executed and delivered shall be an original but all these counterparts shall together constitute one and the same instrument.

9 WAIVER

9.1 The waiver by either party of a breach or default of any of the provisions of this Agreement by the other party shall not be construed as a waiver of any succeeding breach of the same or other provisions nor shall any delay or omission on the part of either party to exercise or avail itself of any right power or privilege that it has or may have hereunder operate as a waiver of any breach or default by the other party.

10 NOTICES

10.1 Any notice request instruction or other document to be given hereunder shall be delivered or sent by first class recorded post to the address of the other party set out in this Agreement (or such other address as may have been notified) and any such notice or other document shall be deemed to have been served (if delivered) on the second business day after posting. Email and fax notices shall not be valid.

11 SEVERABILITY

11.1 If any wording in any provision of this Agreement shall be found by any court or administrative body of competent jurisdiction to be invalid or unenforceable the invalidity or unenforceability of such wording shall not affect the remainder of this Agreement and the remainder of such provision and all other provisions not affected by such invalidity or unenforceability shall remain in full force and effect.

12 ENTIRE AGREEMENT

12.1 This Agreement (as defined in condition 1 above) sets out the entire agreement between the parties with respect to the subject matter covered by it and supersedes and replaces all prior communications, drafts, agreements, representations, warranties, stipulations, undertakings and agreements of whatsoever nature, whether oral or written, between the parties relating to the subject matter of this Agreement.

12.2 Each party acknowledges that in entering into this Agreement it is not relying upon any representation, warranty, promise or assurance made or given by the other party or any other

person, whether or not in writing, at any time prior to the execution of this Agreement which is not expressly set out in this Agreement.

12.3 Nothing in this Clause 12 or elsewhere in this Agreement shall exclude or restrict any liability which either party would otherwise have to the other in respect of any statements made fraudulently by that party prior to the date of this Agreement.

13 ASSIGNMENT AND SUBCONTRACTING

13.1 The Labels Buyer shall not be entitled to assign or hold on trust this Agreement nor all or any of its rights and obligations hereunder without the prior written consent of BPS .

13.2 The Labels Buyer agrees BPS shall be entitled to transfer the benefit and burden of this Agreement to any competent third party of good financial standing upon at least 30 days' prior written notice, and agrees to act promptly and in good faith to take all such steps and execute all such documents as may reasonably be required by BPS to give effect to such novation or other transfer of rights or obligations under this Agreement.

14 GOVERNING LAW AND JURISDICTION

This Agreement shall be governed by and construed in accordance with English Law and each party hereby submits to the exclusive jurisdiction of the English Courts.

SCHEDULE 1 – COMMERCIAL TERMS

Fee: £630.00

Purpose: To promote a survey on Chronic widespread

Pain/Fibromyalgia

Delivery Date (s): Within 24 hours of receipt of signed contract

Number of permitted uses: One

AS WITNESS the hands of the parties the day and year first above written:

SIGNED by)

for and on behalf of THE BRITISH PAIN)

SOCIETY in the presence of:)

SIGNED by *Sedik*)

for and on behalf of [LABELS BUYER])

in the presence of:)

APPENDIX 12

Recruitment Letter send to the UK Medicine and Health professionals sample for the Fibromyalgia questionnaire in phase 2

Appendix

Inviation Leter

Faculty of Health and Life Sciences

PGR Room 431

Northumberland building

City campus

Northumbria University

Newcastle upon Tyne NE1 8ST, UK

Dear: Sir or Madam

Date: Juan 2016

My name is Sedik Abokdeer I am qualified BSc physiotherapy Worked with a background in Low back pain management, and MSc in health and social care (physical therapy specialist). At present, I am a full-time doctoral student in affiliation with Northumbria University. For my doctorate, I am undertaking research that looks at issues of 'fibromyalgia' interventions to people exhibiting interventions performances that have historical and/or present involvement with Local Authority health Services.

On the basis of your present position I have identified you as being involved in the provision of collaborative health services to this intervention and/or as a helper of investigation that inform and/or impact upon the life course of these fibromyalgia syndrome patients.

I am writing to ask you take part in a survey (Questionnaire) conducted by me. The purpose of this Questionnaire is to better understand your present experience or organisational involvement with these interventions, as well as your perceptions of how your involvement(s) impact of interventions upon the life course of this population with fibromyalgia syndrome.

I have attached an information sheet and informed consent to this email. **If you are interested in participating I would ask that you take the time to review the accompanying Information Sheet and return the attached INFORMED CONSENT care of my attention as confirmation of your willingness to participate.** If you have any questions please do not hesitate to contact me directly.

Appendix

This study has received ethical approval from the Faculty of Health and Life Sciences Ethics Committee at Northumbria University.

Sincerely,

Sedik Abokdeer

PhD student Researcher

M: 07448378709

sedik.abokdeer@northumbria.ac.uk

APPENDIX 13

Medicine and Health professionals consent form to participate in the phase 2 study

Appendix

Consent form

Project Title: Service Users and Service Providers Views and Experiences of Chronic Widespread Pain Conditions (Fitzcharles et al.): Practice and Participation.

Named Researcher: MR: Sedik Abokdeer

PhD Researcher

M: 07448378709

Sedik.abokdder@northumbria.ac.uk

This form is designed to confirm that you have been fully informed about the research being undertaken, that you understand what you are being asked to do and that you consent to participate in the research.

Please INITIAL the boxes that correspond to your choices	YES	NO
10. I wish to participate in the Survey associated with this research.		
11. I have read & understood the attached information sheet giving details of the project.		
12. I have had the opportunity to ask any questions about the research, my involvement in it, and am satisfied with the answers I have been given.		
13. I am aware decision to consent is entirely voluntary and I understand that I am free to withdraw at any time without giving a reason.		
14. I understand that if I elect to withdraw from participating in this research my decision will not impact upon my standing with the organisation for which you work		
15. I understand the data gathered in this project will form the basis of a doctoral thesis and may inform reports and/or publications and/or presentations.		
16. I understand that my name will not be used in the named researcher's thesis and in any other report, publication, and/or presentation resulting from the data collected, and that every effort will be made to protect my confidentiality.		
17. I know that if I am in any way unhappy with the conduct of the research, I may approach **Professor Jennifer Watling**; Associate Dean for Research and Innovation; Northumbria University; Coach Lane Campus, Benton; Newcastle upon Tyne; NE7 7XA; Tel:- 0191 215 7771 email : - Janice.armstrong@northumbria.ac.uk		

Please SIGN the following, PRINT your name, and DATE

Participant's Signature: ***----------Date: -----/------/-------***

Participants Name (in CAPITAL: ----------

The named researcher signs/dates in the space provided to confirm that the participant understands the purpose of the research, their role, and that they have the right to withdraw at any time.

Researcher's Signature: ---------- Date: -------/----------/----------

Attachment (Survey)

CONTACT DETAILS FOR SUMMARY OF RESULTS

I would prefer to receive the results by (please tick one):

Post ☐

Email ☐

Postal address:

……
……

……
……

……
……
……
……
……

Email:

……
……

APPENDIX 14

Participations information sheet, Survey, Fibromyalgia Questionnaire for phase 2

Appendix

SURVEY INFORMATION SHEET

Project Title: Service Users and Service Providers Views and Experiences of Chronic Widespread Pain Conditions (Fitzcharles et al.): Practice and Participation.

What is this research about?

To describe the current practice surrounding chronic widespread pain/fibromyalgia in the UK and to compare interventions and services in different regions in the UK; this follows from previously published work by the research team.

Why have I been asked?

You are being asked to take part because you are working NHS specialist in rheumatology or pain management and physical therapy clinics. Or you are a professional with direct contact and/or decision-making responsibility for fibromyalgia patients who have a history of and/or current involvement with Local Authority NHS services.

What am I being asked to do?

You are being invited to participate in a survey (questionnaire) which will take no more than 10-15 minutes to complete. You will be asked to share your professional experiences of working with fibromyalgia patients and interventions that you provide.

What happens if I do not want to participate?

Your participation though valued is entirely voluntary; you are in no way required to take part in this research.

What would happen if I agree to participate and then change my mind?

You are under no obligation to take part. If you do decide to take part, you are free to withdraw at any time without giving a reason. The data collected from the survey will still be used in the research with all personally identifiable information removed. It will not be possible to withdraw the data at this stage. If you have already agreed to participate, but then change your mind, please contact the named researcher to decline your interest.

Will my participation in the research be kept confidential?

Yes. Your involvement with this research will be kept confidential. Only the research team will know about your participation in the research. Your name and the specific details of your role within the organisation you represent will be kept confidential and will not appear in any documents associated with this research.

What will happen to the information that is gathered in the survey?

All the information collected will be kept confidential. After the survey, the researcher will keep up the information with your name and any other identifiable information securely locked at Northumbria University and/or electronically encrypted. Only the research team will have access to this information. Information from the professionals that took part in the survey will then be used to complete the final report; information are used in the final report will be anonymised. Names and details of participants will not appear in any document.

Case report forms (CRFs) - i.e completed questionnaire data will be stored securely at the Northumbria University and destroyed one year after the end of the research. The data can be withdrawn if the request is made before a specified deadline.

What will happen to the information collected for the research and how will the research report be disseminated?

All the information collected will be analysed at to identify participants' common thoughts and views on the subject. These will then be used to produce a final report. The final report will be presented to Northumbria University and will form part of the named researcher's Ph.D. degree. A summary of the research findings will be sent to all the participants and the full report can be requested by participants after has been produced.

Who will read and/or have access to the published results?

This research will be used in the named researcher's doctoral thesis. Additionally, it is the named researcher's intention to make the conclusions of this research available to the Local Authority and other organisations to inform health care practice.

Who can I contact if I want to know anything else about this study?

You are welcome to contact the named researcher and/or the named researcher's Project Supervisor if you require further information related to this study. Contact information for both parties is as follows:

PROJECT SUPERVISOR

Professor Nicola Adams

Faculty of Health and Life Sciences

B131

Coach Lane Campus West

Northumbria University

Coach Lane

Benton

Newcastle upon Tyne

NE7 7XA

0191 215 6620

nicola.adams@northumbria.ac.uk

NAMED RESEARCHER

MR Sedik Abokdeer

Faculty of Health and Life Sciences

PGR Room 431

Northumberland building

Northumbria University

City Campus

Newcastle upon Tyne

NE1 8ST, UK

07448378709

sedik.abokdeer@northumbria.ac.uk

2. Who can I contact if I am unhappy with the conduct of the research?

If you are in any way unhappy with the conduct of the research, you may approach:

ASSOCIATE DEAN FOR RESEARCH AND INNOVATION

Professor Jennifer Watling

Northumbria University
Coach Lane Campus, Benton
Newcastle upon Tyne
NE7 7XA
Tel: 0191 215 7771
Janice.armstong@northumbria.ac.uk

APPENDIX 15

Fibromyalgia Questionnaire, for phase 2

CHRONIC WIDESPREAD PAIN / FIBROMYALGIA QUESTIONNAIRE

ALL RESPONSES ARE STRICTLY CONFIDENTIAL, AND YOU WILL NOT BE IDENTIFIED

THANK YOU FOR YOUR PARTICIPATION

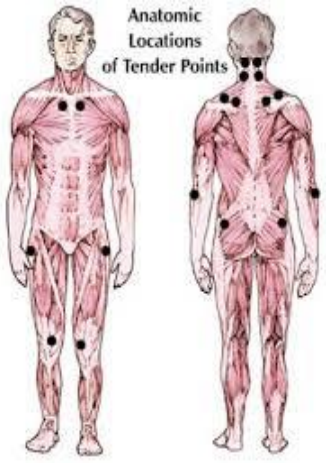
MANAGEMENT OF CHRONIC WIDESPREAD PAIN /FIBROMYALGIA QUESTIONNAIRE

The questionnaire is concerned with patients/clients who fit the following description:-

Chronic Widespread Pain/Fibromyalgia is a debilitating chronic disorder

Characterised by:

- **The presence of continual and widespread musculoskeletal Pain for three months or longer.**
- **Symptoms which include fatigue sleep disturbance, tender points, anxiety and depression, cognitive deficits in attention, concentration and memory, and other symptoms such as irritable bowel syndrome, morning stiffness, headaches, or cramps.**



Please now answer each of the following questions

Region

North East	☐	**1**
North West	☐	**2**
South East	☐	**3**
South West	☐	**4**
Midlands	☐	**5**
London	☐	**6**
Wales	☐	**7**
Scotland	☐	**8**

Northern Ireland	☐	**9**
Non UK	☐	**10**

Personal Details:-

1. What is your profession

profession	**Rheumatologist**	☐	**1**
	Pain management specialist	☐	**2**
	Physiotherapist	☐	**3**
	Occupational therapist	☐	**4**
	Psychologist	☐	**5**
	Others	☐	**6**

Please specify ……

2. What speciality do you mainly work in?

In- patients	☐	**1**
Out patients	☐	**2**
Community	☐	**3**
Private practice	☐	**4**
other please state	☐	**5**

……..

Patients/ clients with Fibromyalgia

3. In the last 12 months have you seen patients that fit the description provided at the beginning of this questionnaire?

Yes, I have seen patients/clients who closely fit this description ☐ **1**

Yes, I have seen patients/clients who more or less fit this description ☐ **2**

NO, I have not seen patients/clients who fit this description ☐ **3**

If no please return the questionnaire in the reply –paid envelope. Thank you very much for your help.

4. How many new patients/clients fit this description did you see in the last 12 months (tick one)?

1-4 patients, per month. ☐ **1**

5-9 patients, per month. ☐ **2**

10-15 patients, per month. ☐ **3**

5. What proportion of these patients come to you with a diagnosis of fibromyalgia?

All of them ☐ **1**

More than half of them ☐ **2**

About half of them ☐ **3**

Less than half of them ☐ **4**

Almost none of them ☐ **5**

None of them ☐ **6**

Comments……
……
……

6. What is the frequency with which patients fitting the definition of fibromyalgia (given the criteria provided above) are referred from each of the following sources? (tick one)

	Often	Sometimes	Seldom	Never	
General practitioner	☐	☐	☐	☐	**A**
Orthopaedic surgeon	☐	☐	☐	☐	**B**
Neurologist	☐	☐	☐	☐	**C**
Psychologist	☐	☐	☐	☐	**D**
Anaesthetist	☐	☐	☐	☐	**E**
Rehabilitation therapist	☐	☐	☐	☐	**F**
Self-referral by patient	☐	☐	☐	☐	**G**

Other (please state)
…….

7. Which of the following best describes the Patients /clients.

Patients come to me without any previous management	☐	**1**
Patients to me at an early stage of their assessment	☐	**2**
Patients come to me after other forms of treatment	☐	**3**
Patients come to me after all or nearly all, other forms of treatment have been attempted	☐	**4**
None of these	☐	**5**

Diagnosis

8. Are there patients/clients whom you consider to have fibromyalgia only?

No	☐	**1**
Yes	☐	**2**

If no, what other Co-morbid conditions do, they have?

……

9. Are there patients /clients whom you consider to have fibromyalgia who come to you under other diagnostic labels?

No	☐	**1**
Yes	☐	**2**

If yes give details

……

10. To what extent do patients /clients generally show an increase in pain with an increase in level of physical activity?

No Pain	☐	**1**
Mild	☐	**2**
Moderate	☐	**3**
Severe	☐	**4**
Most severe	☐	**5**
Extreme pain	☐	**6**

11. Do any patients /clients use assisted equipment? (e.g. walking aid)?

Yes	☐	**1**
No	☐	**2**
Sometimes	☐	**3**

12. What aspect /activity of patients /clients' daily living are most affected due to chronic widespread pain/fibromyalgia? (Tick as many as apply)

Walking	☐	**A**
Running	☐	**B**
Shopping	☐	**C**
Swimming	☐	**D**
None of these	☐	**E**

13. Please indicate how often the fibromyalgia patients you see present with each of the following clinical features

	Always/Nearly Always	Often	Sometimes	Seldom	Never/Almost Never	
Pain –generalized	☐	☐	☐	☐	☐	**A**
Pain- localized	☐	☐	☐	☐	☐	**B**
Tenderness on palpation	☐	☐	☐	☐	☐	**C**
Excessive fatigue	☐	☐	☐	☐	☐	**D**
Loss of muscle power and/or endurance	☐	☐	☐	☐	☐	**E**
Loss of joint range	☐	☐	☐	☐	☐	**F**
Feeling of stiffness	☐	☐	☐	☐	☐	**G**
Loss of function	☐	☐	☐	☐	☐	**H**

Psychological problem (e.g. depression, anxiety)	☐	☐	☐	☐	☐	**I**
Peripheral circulatory disorder	☐	☐	☐	☐	☐	**J**
Other	☐	☐	☐	☐	☐	**K**

14. Of the clinical symptoms identified above, which feature do you usually find is the most important to the patient? Please explain why: -

……

……

……

15. Please list below the three treatments /management objectives that you most commonly identify following assessment of fibromyalgia patients. Please list in descending order of priority (e.g. highest priority objective as number1.).

1
……

2
……

3
……

16. By what means do you measure the intensity of fibromyalgia patients pain (please tick all that apply)?

Numerical rating scale(e.g. 1-10)	☐	**1**
Verbal rating scales (e.g. severe, moderate)	☐	**2**

Visual analogue scale	☐	**3**
Dolorimeter	☐	**4**
McGill Pain Questionnaire (long or short form	☐	**5**
Other (please state below	☐	**6**

……

Do not routinely measure pain intensity ☐ **7**

If you routinely measure dimensions of pain other than its intensity, please provide details:

……

……

17. Do you use any other standardised assessment scales or measures with chronic widespread pain/fibromyalgia patients?

No	☐	**1**
Yes (please state which below)	☐	**2**

……

Any other comments on the assessment of fibromyalgia patients:-

……

……

……

Medications

18. Which of the following medication have you prescribed to patients with fibromyalgia?

Tramadol	☐	**A**
Muscle relaxants	☐	**B**
Antidepressants:-		
Amitriptyline	☐	**C**
Fluoxetine	☐	**D**
Duloxetine	☐	**E**
Milnacipran	☐	**F**
Pregabalin or pramipexole	☐	**G**
Other	☐	**H**

Please state

…….

…….

19. Have these patients/clients, whom you consider to have fibromyalgia, come to you without medications specifically for their symptoms?

Yes	☐	**1**
No	☐	**2**
Sometimes	☐	**3**

20. Please indicate how often you make use of each of the following interventions for these patients. If you do not have access to interventions (e.g. necessary equipment not available, not trained in its use), please tick 'Not applicable.'

	Always/Nearly Always	Often	Sometimes	Seldom	Never/Almost Never	Not applicable	
Stretching exercise	☐	☐	☐	☐	☐	☐	**A**
Aerobic exercise	☐	☐	☐	☐	☐	☐	**B**
Graded exercise programme	☐	☐	☐	☐	☐	☐	**C**
Group exercise programme	☐	☐	☐	☐	☐	☐	**D**
Hydrotherapy	☐	☐	☐	☐	☐	☐	**E**
Postural education	☐	☐	☐	☐	☐	☐	**F**
Functional activity re- education	☐	☐	☐	☐	☐	☐	**G**
Cognitive behavioural Therapy (CBT)	☐	☐	☐	☐	☐	☐	**H**
Relaxation	☐	☐	☐	☐	☐	☐	**I**
Acupuncture	☐	☐	☐	☐	☐	☐	**J**
Ergonomic evaluation	☐	☐	☐	☐	☐	☐	**K**
Tens	☐	☐	☐	☐	☐	☐	**L**
Ultrasound	☐	☐	☐	☐	☐	☐	**M**
Manual therapy	☐	☐	☐	☐	☐	☐	**N**

Massage	☐	☐	☐	☐	☐	☐	**O**
Energy conservation/ fatigue management	☐	☐	☐	☐	☐	☐	**p**

Other (please state)

……

……

21. Do you have specific treatment /management programme for fibromyalgia patients? (tick one)

No	☐	1
Yes, for chronic pain patients in general	☐	2
Yes, specifically for fibromyalgia patients	☐	3

If you have answered yes, please give brief details of the programme.

……

……

……

22. Generally speaking, how responsive do you find fibromyalgia patients are to interventional approaches ?

Extremely responsive	**Very responsive**	**Moderately responsive**	**Quite unresponsive**	**Extremely unresponsive**
☐	☐	☐	☐	☐
1	**2**	**3**	**4**	**5**

Please comment on any factors relating to the patients' condition that tends, in your experience, to be associated with a good therapeutic outcome:

……

……

23. What do you hope to achieve from a fibromyalgia Rehabilitation Programme?

……

……

24. Please indicate your agreement or disagreement with each of the following statements, about fibromyalgia patients:

	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree
Patients have considerable psychological overlay	☐	☐	☐	☐	☐
Treatment must not aggravate the patient's pain	☐	☐	☐	☐	☐
Restoring function is more important than treating pain	☐	☐	☐	☐	☐
The diagnosis is made once all other diagnoses have been tried and rejected	☐	☐	☐	☐	☐
These patients are generally well informed on their condition	☐	☐	☐	☐	☐
Patients are able to self-manage their condition	☐	☐	☐	☐	☐

25. Please add any final comments, on any aspect of the treatment/management of patients with fibromyalgia:

……

……

Thank you very much for sparing your time to complete this questionnaire

Please return it in the reply-paid envelope to:-

SEDIK ABOKDEER

Doctoral student

Department of Sport, Exercise and Rehabilitation

Faculty of Health and Life Sciences

Northumberland Building Room 431,

Northumbria University, Newcastle Upon Tyne NE1 8ST, UK

APPENDIX 16

FIQ Results

Appendix

Fibromyalgie impact questionnaire results

Pt1	Scale	Item	Recode	Score Range	Normalization
	Physical impairment	1	No	0 - 3	2x3.33=6.66
	Feel good	2	Yes	0 - 7	7x1.43=10.01
	Work missed	3	No	0 - 7	5x1.43=7.15
	Do work	4	No	0 - 10	8
	Pain	5	No	0 - 10	7
	Fatigue	6	No	0 - 10	9
	Rested	7	No	0 - 10	9
	Stiffness	8	No	0 - 10	9
	Anxiety	9	No	0 - 10	2
	Depression	10	No	0 - 10	3
	Total score				70.82

Pt2	Scale	Item	Recode	Score Range	Normalization
	Physical impairment	1	No	0 - 3	2x3.33=6.66
	Feel good	2	Yes	0 - 7	6x1.43=8.58
	Work missed	3	No	0 - 7	7x1.43=10.01
	Do work	4	No	0 - 10	10
	Pain	5	No	0 - 10	10
	Fatigue	6	No	0 - 10	7
	Rested	7	No	0 - 10	8
	Stiffness	8	No	0 - 10	7
	Anxiety	9	No	0 - 10	7
	Depression	10	No	0 - 10	10
	Total score				84.25

Pt3	Scale	Item	Recode	Score Range	Normalization
	Physical impairment	1	No	0 - 3	2x3.33=6.66
	Feel good	2	Yes	0 - 7	3x1.43=4.29
	Work missed	3	No	0 - 7	1x1.43=1.43
	Do work	4	No	0 - 10	7
	Pain	5	No	0 - 10	6
	Fatigue	6	No	0 - 10	10
	Rested	7	No	0 - 10	8
	Stiffness	8	No	0 - 10	6
	Anxiety	9	No	0 - 10	3
	Depression	10	No	0 - 10	6
	Total score				58.38

Pt4	Scale	Item	Recode	Score Range	Normalization
	Physical impairment	1	No	0 - 3	2x3.33=6.66
	Feel good	2	Yes	0 - 7	7x1.43=10.01
	Work missed	3	No	0 - 7	7x1.43=10.01
	Do work	4	No	0 - 10	9
	Pain	5	No	0 - 10	9
	Fatigue	6	No	0 - 10	10
	Rested	7	No	0 - 10	10
	Stiffness	8	No	0 - 10	10
	Anxiety	9	No	0 - 10	6
	Depression	10	No	0 - 10	8
	Total score				88.68

Pt5	Scale	Item	Recode	Score Range	Normalization
	Physical impairment	1	No	0 - 3	2x3.33=6.66
	Feel good	2	Yes	0 - 7	5x1.43= 7.15
	Work missed	3	No	0 - 7	4x1.43=5.72
	Do work	4	No	0 - 10	7
	Pain	5	No	0 - 10	8.5
	Fatigue	6	No	0 - 10	10
	Rested	7	No	0 - 10	9.5
	Stiffness	8	No	0 - 10	8
	Anxiety	9	No	0 - 10	8
	Depression	10	No	0 - 10	10
	Total score				80.53

Pt6	Scale	Item	Recode	Score Range	Normalization
	Physical impairment	1	No	0 - 3	2x3.33=6.66
	Feel good	2	Yes	0 - 7	2x1.43=2.86
	Work missed	3	No	0 - 7	6x1.43= 8.58
	Do work	4	No	0 - 10	10
	Pain	5	No	0 - 10	10
	Fatigue	6	No	0 - 10	9.5
	Rested	7	No	0 - 10	10
	Stiffness	8	No	0 - 10	10
	Anxiety	9	No	0 - 10	10
	Depression	10	No	0 - 10	8.5
	Total score				86.1

Pt7	Scale	Item	Recode	Score Range	Normalization
	Physical impairment	1	No	0 - 3	2x3.33=6.66
	Feel good	2	Yes	0 - 7	7x1.43=10.01
	Work missed	3	No	0 - 7	0x1.43=0
	Do work	4	No	0 - 10	10
	Pain	5	No	0 - 10	10
	Fatigue	6	No	0 - 10	10
	Rested	7	No	0 - 10	10
	Stiffness	8	No	0 - 10	6
	Anxiety	9	No	0 - 10	8
	Depression	10	No	0 - 10	10
	Total score				80.67

Pt8	Scale	Item	Recode	Score Range	Normalization
	Physical impairment	1	No	0 - 3	2x3.33=6.66
	Feel good	2	Yes	0 - 7	2x1.43=2.86
	Work missed	3	No	0 - 7	5x1.43=7.15
	Do work	4	No	0 - 10	8
	Pain	5	No	0 - 10	7
	Fatigue	6	No	0 - 10	6
	Rested	7	No	0 - 10	2
	Stiffness	8	No	0 - 10	8
	Anxiety	9	No	0 - 10	5
	Depression	10	No	0 - 10	4
	Total score				56.67

Pt9	Scale	Item	Recode	Score Range	Normalization
	Physical impairment	1	No	0 - 3	2x3.33=6.66
	Feel good	2	Yes	0 - 7	7x1.43=10.01
	Work missed	3	No	0 - 7	0x1.43=0
	Do work	4	No	0 - 10	10
	Pain	5	No	0 - 10	10
	Fatigue	6	No	0 - 10	10
	Rested	7	No	0 - 10	10
	Stiffness	8	No	0 - 10	10
	Anxiety	9	No	0 - 10	5
	Depression	10	No	0 - 10	4
	Total score				75.67

Pt10	Scale	Item	Recode	Score Range	Normalization
	Physical impairment	1	No	0 - 3	2x3.33=6.66
	Feel good	2	Yes	0 - 7	5x1.43=7.15
	Work missed	3	No	0 - 7	3x1.43=4.29
	Do work	4	No	0 - 10	9
	Pain	5	No	0 - 10	8
	Fatigue	6	No	0 - 10	8
	Rested	7	No	0 - 10	10
	Stiffness	8	No	0 - 10	8
	Anxiety	9	No	0 - 10	4
	Depression	10	No	0 - 10	4
	Total score				69.1

Pt11	Scale	Item	Recode	Score Range	Normalization
	Physical impairment	1	No	0 - 3	2x3.33=6.66
	Feel good	2	Yes	0 - 7	5x1.43=7.15
	Work missed	3	No	0 - 7	4x1.43=5.72
	Do work	4	No	0 - 10	10
	Pain	5	No	0 - 10	10
	Fatigue	6	No	0 - 10	10
	Rested	7	No	0 - 10	10
	Stiffness	8	No	0 - 10	10
	Anxiety	9	No	0 - 10	10
	Depression	10	No	0 - 10	6
	Total score				85.53

Pt12	Scale	Item	Recode	Score Range	Normalization
	Physical impairment	1	No	0 - 3	2x3.33=6.66
	Feel good	2	Yes	0 - 7	5x1.43=7.15
	Work missed	3	No	0 - 7	3x1.43=4.29
	Do work	4	No	0 - 10	6
	Pain	5	No	0 - 10	6
	Fatigue	6	No	0 - 10	7.5
	Rested	7	No	0 - 10	6.5
	Stiffness	8	No	0 - 10	6
	Anxiety	9	No	0 - 10	8.5
	Depression	10	No	0 - 10	8.5
	Total score				67.1